DATA-CAN

The Health Data Research Hub for Cancer

DATA-CAN

Impact report
- a two year journey

Get started

UCLPartners · Genomics england · IQVIA · NHS The Leeds Teaching Hospitals NHS Trust · NHS Lothian · QUEEN'S UNIVERSITY BELFAST · Swansea University Prifysgol Abertawe | Medical School Ysgol Feddygaeth · THE UNIVERSITY of EDINBURGH · UNIVERSITY OF EXETER · UNIVERSITY OF LEEDS

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Welcome

Dr Charlie Davie, Director – DATA-CAN

Pete Wheatstone, Chair – DATA-CAN Patient and Public Involvement and Engagement Group

Welcome to DATA-CAN's Impact Report, showcasing an exciting, yet challenging, journey from our launch in October 2019.

Over the last two years, DATA-CAN has had a significant impact pioneering and informing the development of health data research and demonstrating how insights from data can improve cancer diagnosis and treatments.

We are proud to work with such a committed partnership of people and organisations from across the United Kingdom, represented by patients, academia, the NHS, industry and life sciences. Created by six founding partners as one of Health Data Research UK's data hubs, we were delighted to be joined in 2021 by additional partners - the universities of Edinburgh and Exeter, and NHS Lothian. Together, we are unlocking the huge potential that data has to transform cancer care.

COVID-19 has been uniquely challenging for all, not least those of us involved in healthcare. As the pandemic took hold, DATA-CAN quickly repurposed its activities to play a significant role in the data research response to the emergency. Our research, utilising 'real-time' data from hospital trusts across the UK, revealed the significant impact on cancer patients and contributed to the restoration of NHS cancer services.

Right from the start of our journey, we have tried to make sure that patients and carers are involved at all levels of DATA-CAN's decision-making process.

By working together across our collaboration, we are able to ensure that health data is used responsibly, and that the benefits of improved access to data for researchers are returned to patients, the NHS and the wider UK community.

> "I'm proud to be working with such a committed team of cancer clinicians and researchers, data experts, patients, charities, industry partners and others from across the UK. Together, we want to unlock the huge potential of data to transform cancer care."
>
> **Dr Charlie Davie, Director of DATA-CAN**
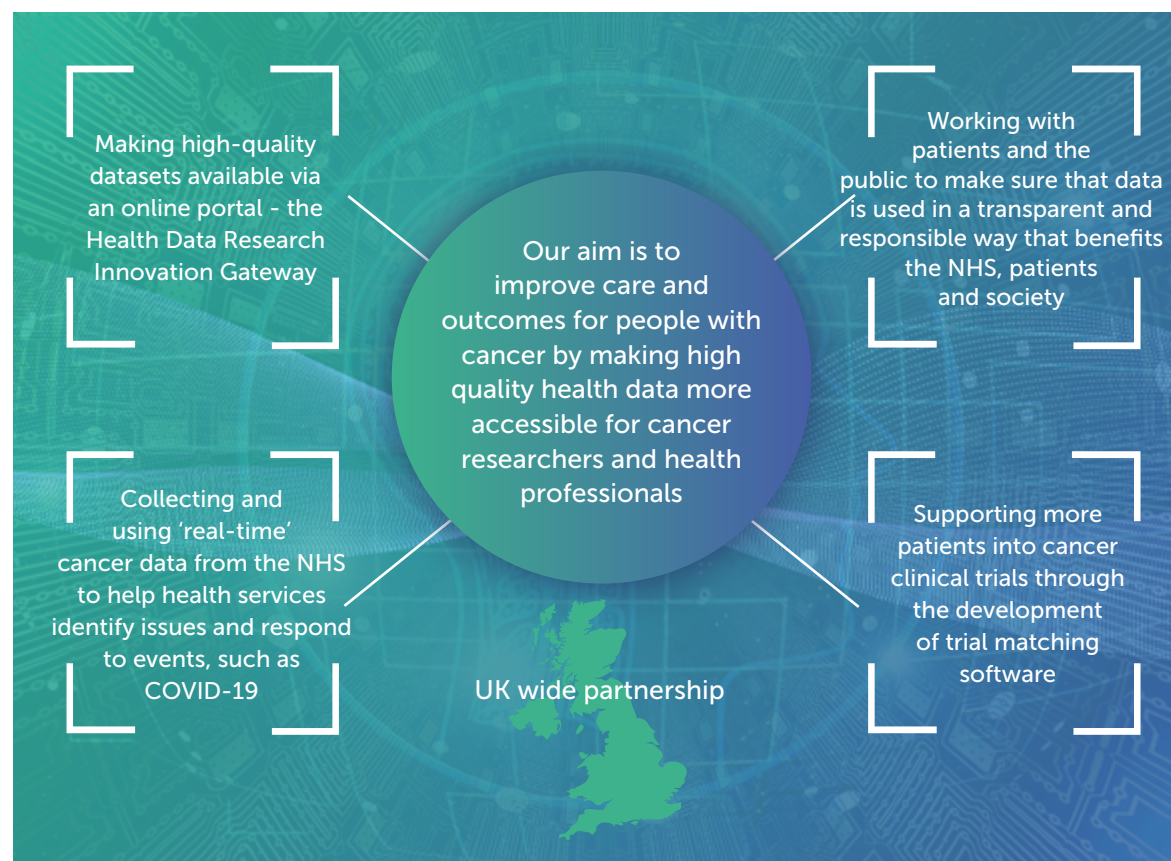
Hosted by UCLPartners

Strategy and vision

As the UK's Health Data Research Hub for Cancer, our aim is to make high quality health data more accessible for cancer researchers and health professionals, to help improve cancer services and patient outcomes.

Hosted by UCLPartners, we are one of the Health Data Research Hubs partly funded through UK Research and Innovation's Industrial Strategy Challenge Fund and coordinated by Health Data Research UK. A unique partnership of NHS organisations, patients, charities, academia and industry – together we are unlocking the power of health data to improve cancer care.

In the UK, over 400,000 new cases of cancer are diagnosed each year, with one in two people facing a cancer diagnosis in their lifetime. A lot of health data about each and every one of us is collected, but this data is not always easy for researchers to find, access and analyse in a timely manner.
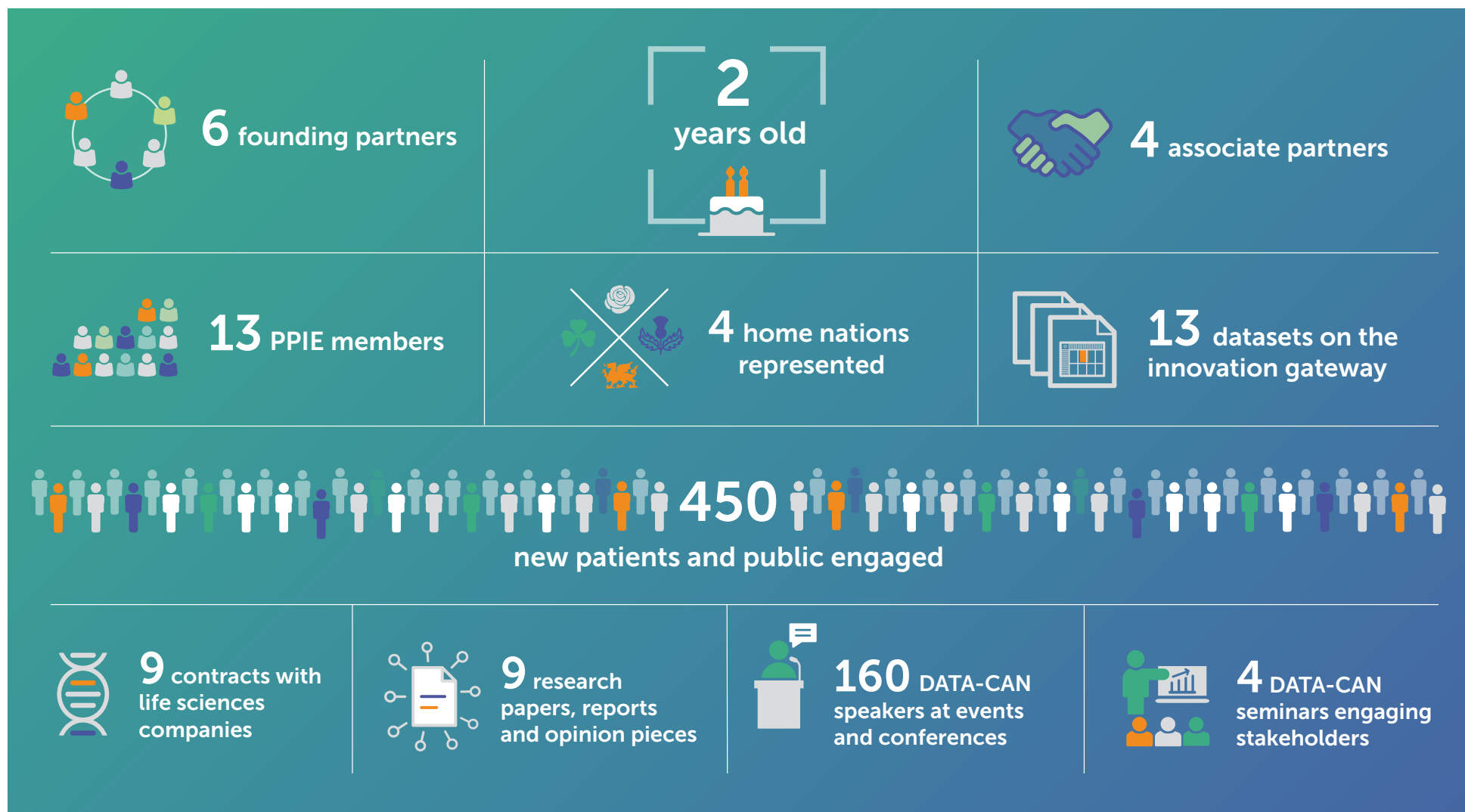
By making high quality health data more accessible for cancer researchers and health professionals, we accelerate research into new diagnostic tools and treatments, and also give patients faster access to clinical trials and innovative treatments.

Making high-quality datasets available via an online portal - the Health Data Research Innovation Gateway

Working with patients and the public to make sure that data is used in a transparent and responsible way that benefits the NHS, patients and society

Our aim is to improve care and outcomes for people with cancer by making high quality health data more accessible for cancer researchers and health professionals

Collecting and using 'real-time' cancer data from the NHS to help health services identify issues and respond to events, such as COVID-19

Supporting more patients into cancer clinical trials through the development of trial matching software

UK wide partnership

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DATA-CAN in numbers

6 founding partners

2 years old

4 associate partners

13 PPIE members

4 home nations represented

13 datasets on the innovation gateway

450 new patients and public engaged

9 contracts with life sciences companies

9 research papers, reports and opinion pieces

160 DATA-CAN speakers at events and conferences

4 DATA-CAN seminars engaging stakeholders

Improving access to data

We aim to make high-quality health data more accessible for cancer researchers and health professionals, to help them research new diagnostic tools and treatments to improve care and outcomes for people with cancer.

One important way that we are doing this is through the Health Data Research Innovation Gateway. This is an online portal which brings together datasets and research from across the UK, with each of the Health Data Research Hubs contributing. DATA-CAN contributes to this portal by providing datasets which can be discovered and requested for access by cancer researchers.

We are also improving the quality of data by sourcing the most relevant data, extracting what researchers need and bringing it together in secure research environments. Through careful curation, we can ensure that datasets are as complete and accurate as possible when they reach researchers.

It is, of course, essential that data is securely handled and is only made accessible when appropriate. DATA-CAN ensures all data is collected, stored, and made available for research according to all current legislation and best practice. We work closely with patients and the public to make sure that their health data is used effectively, transparently and responsibly.

The following pages detail some of the other ways that DATA-CAN is making data more accessible through the national cancer Trust Research Environment and developing trial matching software with our partner IQVIA.

IMPACT STORY

Trusted Research Environment
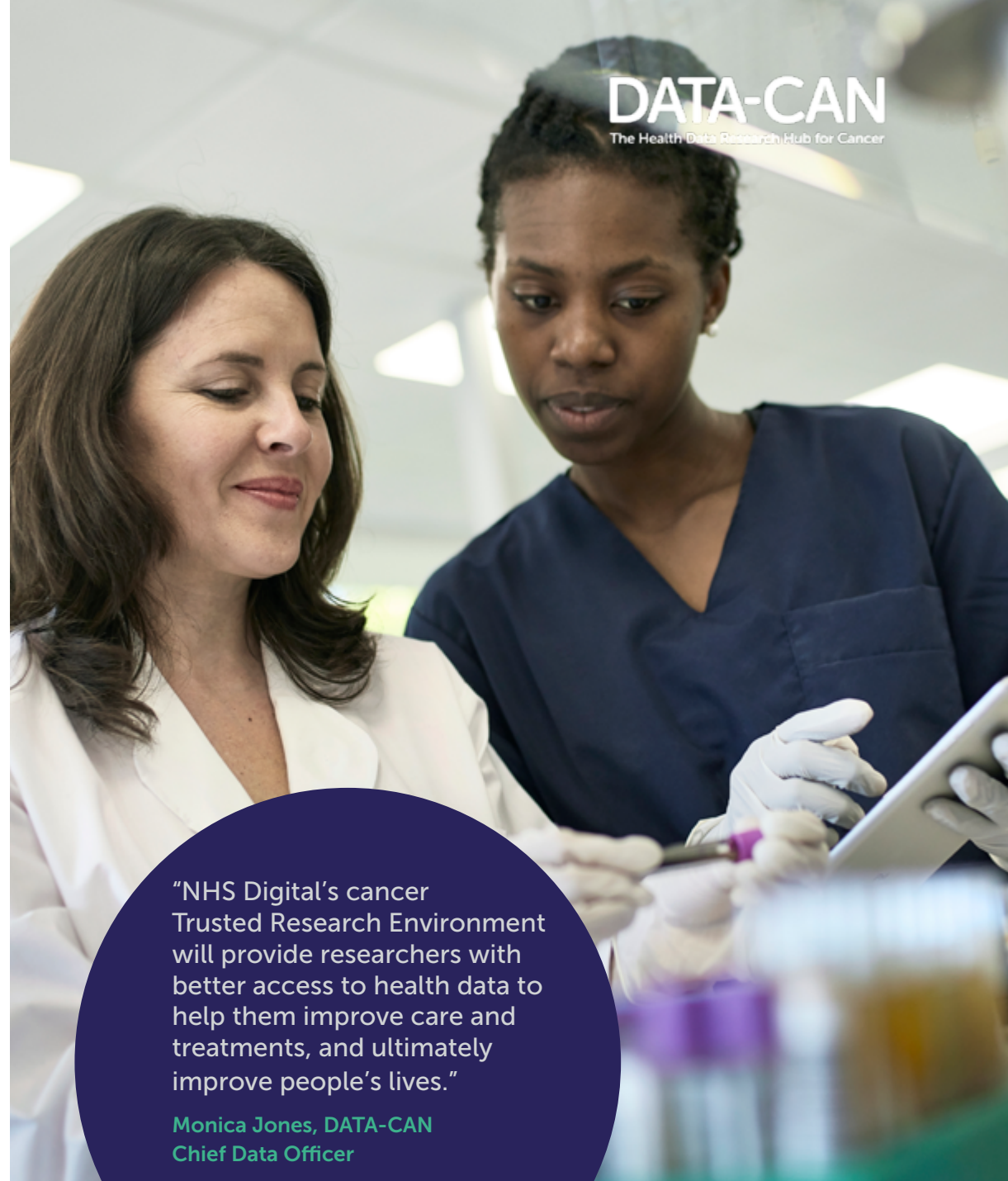
DATA-CAN is working with NHS Digital to provide access to cancer data in the NHS Trusted Research Environment (TRE). TREs are the most secure systems and technology for governing and controlling access to data. The NHS Digital TRE will provide approved researchers from trusted organisations with timely and secure access to de-identified cancer data.

Two of our founding partners, the University of Leeds and Leeds Teaching Hospitals NHS Trust, are leading on this work, which will enable important research on rates of cancer referrals, diagnoses and treatment.

The Trusted Research Environment is being developed in two phases:

Phase 1 – cancer data from the nationally collected NHS Hospital Episode Statistics (HES) and COVID-19 testing is made available to approved researchers via the Health Data Research Innovation Gateway.

Phase 2 – in addition to HES data, national cancer datasets (Cancer Outcome and Services Data set, Chemotherapy and Radiotherapy datasets) will be available to approved researchers.

"NHS Digital's cancer Trusted Research Environment will provide researchers with better access to health data to help them improve care and treatments, and ultimately improve people's lives."

Monica Jones, DATA-CAN Chief Data Officer

DATA-CAN
The Health Data Research Hub for Cancer

Developing trial matching software through the Cancer Data Network

Enabling cancer patients to access the latest innovative therapies in clinical trials rapidly and effectively, and while protecting patient privacy, has huge potential to advance patient care and cancer research. IQVIA, one of DATA-CAN's founding partners, is supporting more patients to access cancer clinical trials through the development of trial matching software and the Cancer Data Network (CDN).

The CDN harnesses data and technology to enable NHS organisations that treat cancer to improve the quality of their care and the outcomes for patients across the UK. As well as matching patients to suitable clinical trials, the network enables near real-time cancer analytics based on data refreshed every 24 hours and national benchmarking.

Joining the CDN will enable NHS trusts to view near real time data on cancer services and the use of treatments, supporting operational decisions. In addition, organisations benefit from the trial matching software which supports study design, feasibility and recruitment.

DATA-CAN and IQVIA are working together to bring new NHS trusts to the Cancer Data Network.

"As a clinician I believe the Cancer Data Network has the potential to transform understanding of care and outcomes of patients in near real time, to benchmark care against other providers and facilitate research and audit."
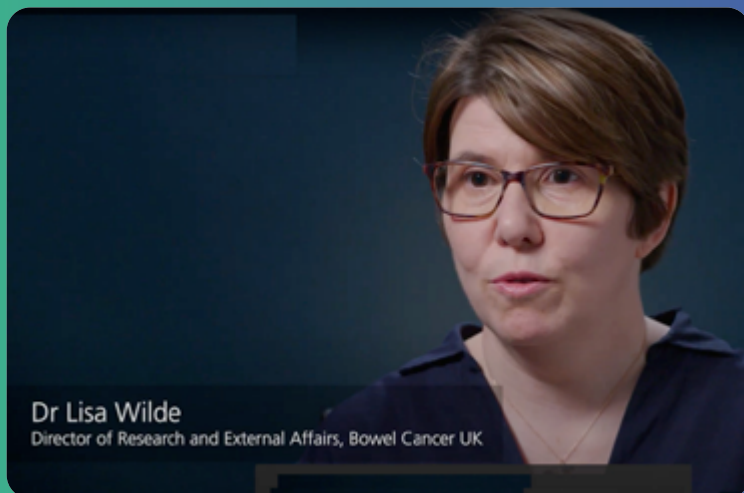**Professor Mick Peake OBE, Chair of Cancer Data Network Advisory Group**

Working with partners

DATA-CAN works in partnership with a host of organisations and individuals, creating a coalition with shared values of using data for the benefit of cancer patients. Since our launch, we have worked with the NHS, life science companies, charities, research scientists and universities to improve cancer diagnosis and research.

Working with charity partners - Dr Lisa Wilde, Bowel Cancer UK

Dr Lisa Wilde
Director of Research and External Affairs, Bowel Cancer UK

▶ Watch video from Lisa

IMPACT STORY

Swallows - the head and neck cancer charity

In 2020, DATA-CAN partnered with the Swallows head and neck cancer charity to highlight the impact that COVID-19 has had on the patients and carers they represent.

New data, from DATA-CAN and partners, on behalf of Swallows revealed that progress in projected five-year survival from head and neck cancer could be set back significantly and have a devastating impact on patients, leading to hundreds of excess deaths. Pre-COVID, around 47 per cent of people with head and neck cancer would be projected to survive for five years or more. However, due to a decline in urgent referrals during the lockdowns, this figure could now drop to 43 per cent surviving for five years or more. This could potentially lead to an additional 451 deaths in people with head and neck cancer as a result of the pandemic.

Working together, DATA-CAN and Swallows created an animation, an infographic and online materials to highlight the impact on head and neck cancer patients and their families.

The Swallows
Head & Neck Cancer Support Group
Registered Charity Number: 1149784

The Queen's Award for Voluntary Service
The MBE for volunteer groups

"Working with DATA-CAN's Scientific Director Prof Mark Lawler allowed us to realise the alarming impact of coronavirus on all head and neck cancer patients."
Chris Curtis, Founder of Swallows

DATA-CAN
The Health Data Research Hub for Cancer

Life sciences companies often find it challenging to deliver data science using health data in the UK. The access process can be unpredictable and long, and the data is not always ready for analysis.

DATA-CAN is giving life sciences companies an opportunity to use our skills and expertise to develop solutions to data challenges in partnership with the NHS and universities. This helps them to conduct the research needed to develop new treatments.

Legal decisions on access to NHS data continue to be managed by data custodians, including NHS trusts, who operate within strict protocols covering appropriate access to data. In addition, all of our work with commercial partners must be approved by the DATA-CAN's Patient and Public Involvement and Engagement (PPIE) group, who can veto projects. DATA-CAN only works with companies with patient-approved, legitimate data access.
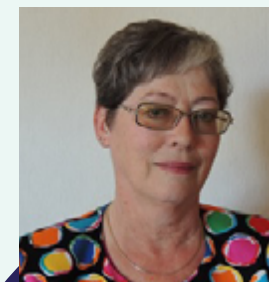
IMPACT STORY

Using data to improve treatment options for early triple negative breast cancer

Around 55,000 women are diagnosed with breast cancer in the UK every year, and around one in five of these will be triple negative.

Patients with triple negative breast cancer don't have oestrogen or progesterone receptors and also don't make too much of the protein called HER2, which is a target of breast cancer treatment. This means that there are fewer treatment options and worse outcomes compared to patients with other breast cancer subtypes.

DATA-CAN worked with the Leeds and Edinburgh NHS Cancer Centres to collect and curate historic data from patients with early stage triple negative breast cancer. The anonymised results were then shared with the pharmaceutical company, Roche Products Ltd, to develop their understanding of the features of early triple negative breast cancer and to better support drug development and access to treatments. The curated data and insights are also available to NHS clinicians and academic researchers via the HDR UK Innovation Gateway.

"This is a vital piece of work, as patients know there is no effective treatment for triple negative breast cancer except older drugs which don't have a good success rate and, consequently, it is much feared."

Jacqui Gath, PPIE Group member

Patients and the public at the heart of our work

Patients and carers are involved at all levels of DATA-CAN's decision-making process. We have an active Patient and Public Involvement Engagement (PPIE) group who help ensure we act fairly and openly, in the best interests of patients.

By working together, we are able to ensure that health data is used responsibly, and that the benefits of improved access to data for researchers are returned to the NHS and the wider UK community.

Patient and public involvement and engagement members are represented on the DATA-CAN steering board and management group. They also review, approve and can veto any DATA-CAN proposal or contract.

We operate by the principles of transparency developed by use MY data and our patient and public members are proactively offered training to empower them in their role with DATA-CAN.

An article highlighting DATA-CAN's innovative way of working, which places the patient front and centre in all their data activities and decisions, has been published in the Partnerships in Practice section of the highly respected British Medical Journal (BMJ).

Working with patients - Yvonne Adebola, PPIE group member

▶ Watch video from Yvonne

"We recognised from the outset that to be confident to voice their views and concerns, patient and public partners must be empowered. Patients are our north star – we follow their lead."

Professor Mark Lawler,
DATA-CAN Scientific Director

DATA-CAN
The Health Data Research Hub for Cancer

IMPACT STORY

Patient and public educational programme

As an organisation that genuinely values patient and public involvement and engagement (PPIE), DATA-CAN recognised the need to provide learning and support for our patient and carer members.

Together with members of our PPIE Group, we identified a significant lack of opportunities for patient representatives to learn about and share health data issues and the nuances of research projects that use health data.

DATA-CAN has developed a programme of learning resources for patients and the public wishing to learn more about health data and its uses for analytics and research. Unlike other health education programmes aimed at professionals, this is aimed directly at patients, carers and advocates with an interest in patient data.

Our intention is to continue to develop education on a wide range of topics reflecting the different levels of expertise and experience, and exploring various delivery mechanisms and forums. This will all be co-developed with PPIE representatives and health data researchers.

IMPACT STORY

Patient and industry partnership

DATA-CAN worked with Flatiron Health UK, a healthcare technology and services company focused on accelerating cancer research and improving patient care, on a project to connect with patients.

We established a patient panel to consider how Flatiron proposed to work with the NHS. An essential part was for Flatiron to explain their value proposition to a group of patients, seeking views on whether the process, controls, actions and benefits were clear.

The process resulted in a report, co-produced with the patient group, which listed a number of areas where Flatiron could continue to refine its approach in the UK, together with specific recommendations for each area.

Based on their engagement with the DATA-CAN patient group, Flatiron is adopting many of these recommendations to develop and refine their PPIE programme and has now launched their own PPIE Group.

**Patient and industry partnership
- Lauren Brown, Director of Flatiron Health UK**

▶ Watch video from Lauren

COVID-19

The COVID-19 pandemic has shown that timely, secure access to quality health data is paramount for all health services, including cancer.

DATA-CAN was at the forefront of the data research response to COVID-19. During the lockdown in Spring 2020, DATA-CAN and the UCL Institute for Health Informatics collected and analysed 'real-time' data from UK cancer centres, covering more than 3.5 million people. This data revealed that the pandemic had had a significant impact on cancer care and could lead to excess deaths amongst people with cancer.

Nationally, our work had significant impact. Results were shared with the four chief medical officers in the UK and England's National Cancer Director. The work also contributed to the restoration of cancer services.

Internationally, DATA-CAN presented this work to influential bodies including WHO Europe and the European Beating Cancer Committee. The European Cancer Organisation invited DATA-CAN's scientific director, Prof Mark Lawler, to co-lead a Special Network on COVID-19 and Cancer, which produced a widely read report influencing Europe's response to COVID-19's impact on cancer. Prof Lawler also co-leads the European Cancer Organisations Time to Act Campaign, with its highly relevant strapline "Don't let COVID-19 stop you from tackling cancer", translated into over 30 European languages and having significant European impact.

DATA-CAN's work on COVID-19 and cancer won the prestigious Royal College of Physicians Excellence in Patient Care Research Award in 2021.

> "This research demonstrates the value to cancer patients, the wider public and decision-makers when trusted professionals use our patient data to help decide the best course of action. It also highlights the urgent need to be able to analyse these data quickly and accurately to inform and influence current events."
>
> **Pete Wheatstone, Chair of DATA-CAN's PPIE group**

Impact of COVID-19 on cancer services - Dr Charlie Davie, Director - DATA-CAN

▷ Watch video from Charlie

Equality, Diversity and Inclusion

DATA-CAN is committed to having a positive impact on equality, diversity and inclusion (EDI), through our work in health data research.

As one of the Health Data Research UK hubs, we fully endorse the HDR UK statement on diversity and inclusion and will continue to work with them and other stakeholders to embrace diverse perspectives, populations, communities and skills in the data research community.

We joined the HDR UK black interns programme to give opportunities to young black people from the UK in health data science. We were delighted to welcome two extremely talented individuals – Noni Anigbo and Anndior Boateng who worked on PPIE and commercial relations projects whilst at DATA-CAN.

As we continue to grow and develop as a research hub, we will be taking the following steps to drive EDI across our projects:

- Assessing DATA-CAN datasets to ensure complete representation of demographic data and taking action where necessary to enhance this data

- Including demographic data in our work using real-time data from the NHS to help health services identify and address specific issues from an EDI perspective

- Encouraging commercial organisations who would like to work with DATA-CAN to think about how EDI factors into their projects through inclusion in the enquiry form.

"No matter what background you come from, data is something that everyone should be interested in because it plays such a big role in how decisions about our lives, communities and healthcare are made."

Anndior Boateng, DATA-CAN intern

▶ **Watch video from Anndior**

"Everyone at DATA-CAN was so supportive and willing to help me, and also to learn from me. It's a great opportunity to meet new people, learn from them and make new connections."

Noni Anigbo, DATA-CAN intern

▶ **Watch video from Noni**

Future plans

Along with the other original Health Data Research UK hubs, DATA-CAN was funded by UK Research and Investment for three years with a view to becoming a more self-sustaining entity beyond this time. DATA-CAN's aim over the next 12 months is to build a sustainable future for the hub, working with partners both in cancer, and other disease areas, to improve treatments and health outcomes for all patients. We will achieve this through three key areas:

1 Improving access to cancer data through the national Trusted Research Environment and Cancer Data Network

Our involvement in the national Trusted Research Environment (TRE) is a crucial part of DATA-CAN's future. The TRE is opening up access to de-identified cancer data to approved researchers from trusted organisations. We will also continue to work with IQVIA in the development of the Cancer Data Network which is supporting more cancer patients into cancer clinical trials and utilising real-time cancer data analytics to aid research.

2 Improving NHS data for cancer research

Another important focus is our work on curated electronic health records (EHR). We will build upon the important work between the University of Edinburgh and Leeds University Teaching Hospitals, collecting and curating data from patients with early triple negative breast cancer to assist research into new treatments. We are seeking to work with additional NHS trusts, beyond the DATA-CAN partnership, to curate and analyse de-identified health data from their electronic health records (EHR). This will enable a focus on additional tumour types and groups of patients, providing valuable insights for cancer research in the NHS and life sciences sector.
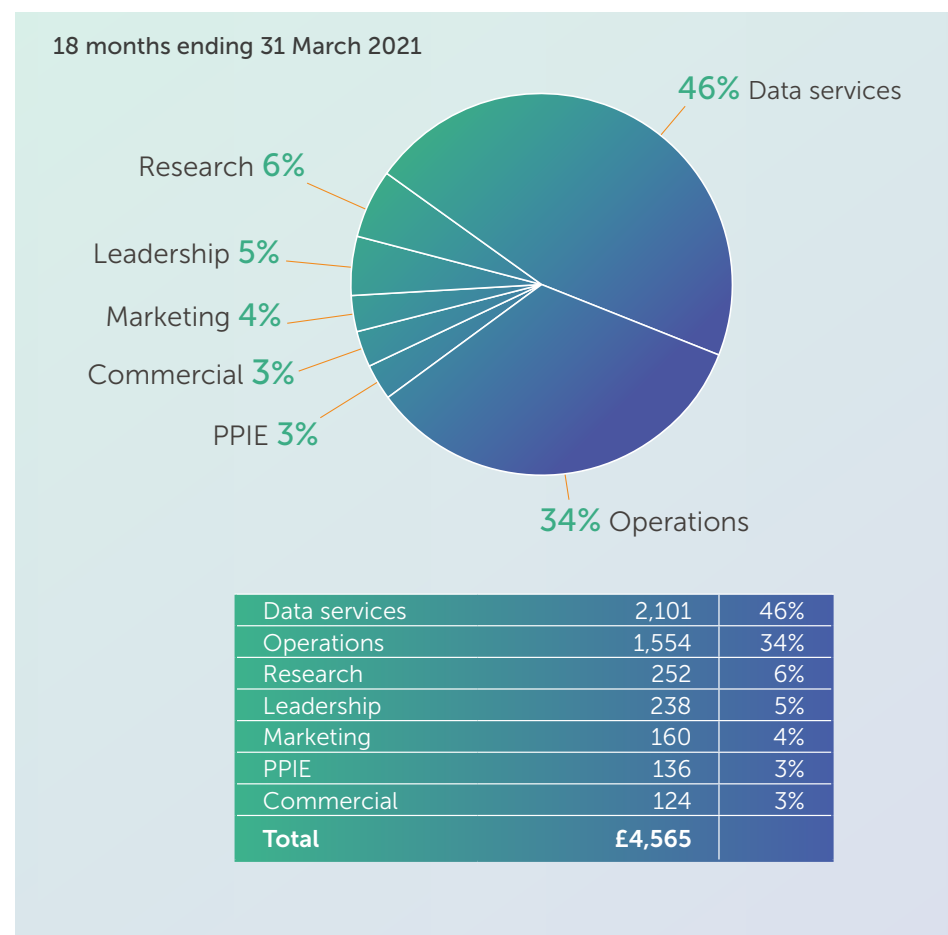
3 Continuing to put patients at the heart of our work

Patient and public involvement will remain embedded and core to all of our future plans. We are working on ways we can amplify our successful PPIE programme at DATA-CAN to provide support for other organisations seeking patient views on cancer research, business plans or specific data-related issues they are facing. We will continue to support the wider PPIE infrastructure through the use MY data patient movement and the other data hubs to build a wealth of knowledgeable and supportive PPIE representatives who can help to ensure that health data is used in a fair and responsible way, with the benefits being returned to the NHS.
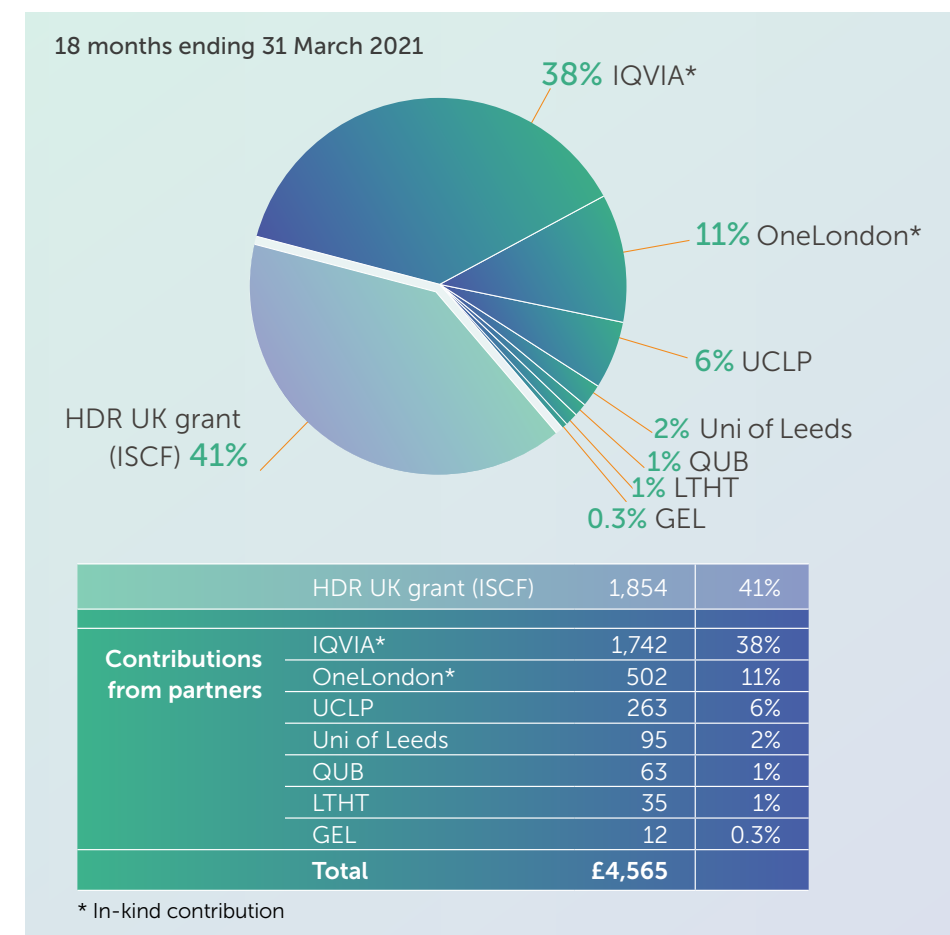
Data saves lives and DATA-CAN is excited to continue to play our part in unlocking the power of health data to improve cancer care

Finances

Where does DATA-CAN's money go?

18 months ending 31 March 2021

46% Data services
Research 6%
Leadership 5%
Marketing 4%
Commercial 3%
PPIE 3%
34% Operations

Data services	2,101	46%
Operations	1,554	34%
Research	252	6%
Leadership	238	5%
Marketing	160	4%
PPIE	136	3%
Commercial	124	3%
Total	**£4,565**	

Where does DATA-CAN's money come from?

18 months ending 31 March 2021

38% IQVIA*
11% OneLondon*
6% UCLP
2% Uni of Leeds
1% QUB
1% LTHT
0.3% GEL
HDR UK grant (ISCF) 41%

	HDR UK grant (ISCF)	1,854	41%
Contributions from partners	IQVIA*	1,742	38%
	OneLondon*	502	11%
	UCLP	263	6%
	Uni of Leeds	95	2%
	QUB	63	1%
	LTHT	35	1%
	GEL	12	0.3%
	Total	**£4,565**	

* In-kind contribution

£150k income reserved for future hub sustainability is not included in the above charts and tables.

DATA-CAN

The Health Data Research Hub for Cancer

For further information about our work visit:
www.data-can.org.uk

Keep in touch:
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🐦 @data_can_hub

💼 DATA-CAN