

# PEOPLE LIKE YOU

Personalised Breast Cancer  
Medicine and Healthcare

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[peoplelikeyou.ac.uk](http://peoplelikeyou.ac.uk)

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A Recital of *Written Portraits*, 2021 © Ricardo Leizaola

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'People Like You' is a collaborative project. Our work focused on personalised medicine and healthcare, largely in breast cancer services. This research was funded by the Wellcome Trust. Grant number: 205456/B/16/Z.

Ethics was approved by North West—Greater Manchester West Research Ethics Committee, 18/NW/0550.

We are grateful to everyone who participated in our research. Thanks to our patient advisory group, Kelly Gleason (Cancer Research UK), Charles Coombes (Imperial College London), and Sinéad Cope (Maggie's West London) for their collaboration and support.

“ I think we’re keeping people alive for longer ... I feel like we can put the brakes on, but I don’t know how long the brakes are going to last for. ”

NHS oncologist

# INTRODUCTION TO OUR RESEARCH



A Recital of Written Portraits, 2021 © Ricardo Leizaola

'Personalised' approaches were transforming the treatment of breast cancer. We explored the impact of new research activities, therapies, and hospital management.

1) We observed care and research along cancer pathways (for example, in the outpatient and chemotherapy departments, and in meetings). We interviewed staff (26) and patients (28). And we re-interviewed 4 staff members and 7 patients who had participated in a previous study (2013-14).

2) We followed research activities involving donations to the Imperial College Healthcare Tissue Bank that were used in different kinds of research; and a study called EBLIS trying to detect cancer earlier by tracking bits of cancer DNA in blood samples.

3) We developed participatory approaches to share experiences about personalised medicine at Maggie's West London and Charing Cross Hospital:

- six public science café events where presentations on contemporary research were discussed among researchers, patients, carers, and others. We learned about the difficulties for patients and staff of implementing research findings in established services.
- a poetry residency with Di Sherlock, who developed 'written portraits' of staff and patients she met in the hospital and at Maggie's.



Oncology outpatient department, 2014 © Sophie Day

# CHANGES SINCE 2014

## What has changed in breast cancer services?

Two systems that patients use to contact hospital staff - Open Access Follow-Up and Navigator services - have improved remote access.\*

Patients described better interactions with the service than 5 years previously. For example, it was easier to contact staff such as their Clinical Nurse Specialist for help.

The service is generally better integrated through digital communication systems. Clinical teams are more stable and less reliant on agency workers.

We learned that more kinds of cancer are recognised and they require different treatments. Patients and staff have more work to do to find out about a cancer, monitor changes and select the best therapies.

Care journeys are still complicated and vary a lot according to the kind of cancer you have, available diagnostics, treatments and research studies.

“virtually every patient has a different type of cancer due to the genetic changes that occur in the cancer compared with normal tissue.”

NHS oncologist

Sophie Day et al. (2021) 'Past-futures in Experimental Care: Breast Cancer and HIV Medicine', *New Genetics and Society*, 40:4, 449-472.

William Viney et al. (2022) 'Personalising Clinical Pathways in a London Breast Cancer Service.' *Sociology of Health & Illness*, 44:3, 624-640.

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# CONNECTING CARE AND RESEARCH

We found a close relationship between care and research activities - drug trials, observational studies, and data from routine care that was collected and analysed for audit purposes.

Patients thought that care, research activities and records were typically combined.

We followed The Early Breast Lead Interval Study (EBLIS) that monitored breast cancer patients who had finished their hospital care.

We also interviewed patients donating tissue and data to Imperial College Healthcare Tissue Bank (ICTB) for various studies, and research staff who were involved.

Sophie Day and Helen Ward worked closely with Jayne Smith, who attended the hospital cancer services. Together they found out what had happened to Jayne's research contributions. They wrote together to describe all the different studies she has been involved in.

“ I just thought that all my cancerous boobs and bodily fluids had disappeared anonymously into an abyss of data, together with those of millions of other cancer patients - just a drop in the ocean. ”

Jayne Smith

After auditing Jayne's participation, scientists agreed that they needed to audit tissue bank samples, so they could share news more widely.

Sophie Day, Jayne Smith, and Helen Ward. (Forthcoming.) 'The Gardener and the Walled Garden'

William Viney and Sophie Day. (Forthcoming.) 'Figuring Molecular Relapse in Breast Cancer Medicine'

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# COVID-19

## March 2020 - June 2020

At the start of the pandemic the service adapted cancer care according to the different types of cancer the patients had, and their response to treatment. Patients unlikely to benefit from hormone therapies, for example, were fast-tracked for surgery.

The Navigator service (see 'Changes Since 2014') became a crucial hub for communication.

Some patients enjoyed making fewer visits to hospitals. Others suffered from isolation and anxiety, made worse by confusing guidelines about shielding and risk of infection.

Patients received a lot of their care remotely by telephone, through primary care and in other ways. They had oral chemotherapy so they did not have to come to hospital.

“ we’ve done what we normally do, but it’s just a lot more complicated! ”  
NHS nurse

“ I was pleased that I didn’t have to go in the hospital. ”  
Person living with cancer

Some patients also got prescriptions from their GPs. They had their bloods checked in primary care. Couriers delivered prescribed medication to patients.

“ doing it by phone is probably safer for them as well. Then you wonder, do they have symptoms that they're not revealing to you, because they just don't want to come up to hospital or don't want to face bad news, you know? ”

NHS oncologist

“ I don't feel as alone in a journey where I don't know what the outcome is because I don't think anybody- I think everybody's, kind of, living day to day with this whole COVID scenario. ”

Person living with cancer



# AFTER COVID-19

The collection of tissue samples in theatres and via phlebotomy stopped from March – Sept 2020. Trials and other research studies have now re-opened.

We do not know how the pandemic will affect cancer diagnoses and treatments in the longer term. But there are reports of backlogs and later diagnoses which will affect outcomes.

Treatment in the service never stopped but referrals from March-May 2020 fell by 38% compared to the same time in 2019.\*

“ I cannot praise that navigator system enough ... I've used them a couple of times and they've never failed me. These people are amazing, it's just such a service, it's wonderful. ”

Person living with cancer

“ I feel that the NHS, they are obviously overburdened with all kinds of other things that are more important than me. ”

Person living with cancer

\*unpublished data. We are grateful to members of staff who shared this information

# INVOLVEMENT AND EDUCATION

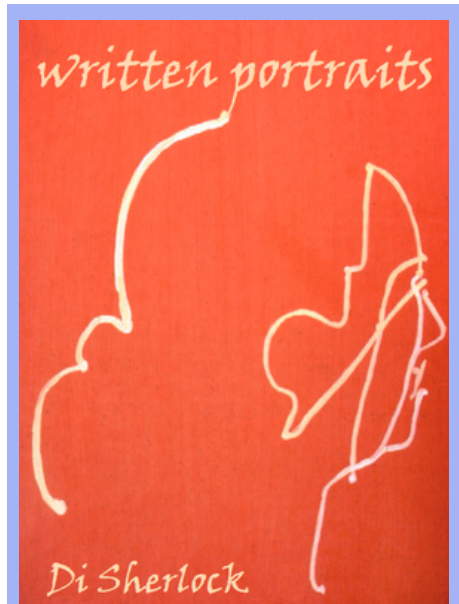
Through a poetry residency and a series of science café meetings at Maggie's West London, staff, patients and other people gave us insights into practices of personalisation.

## 'Written Portraits'

Di Sherlock was a writer-in-residence at Maggie's West London and Charing Cross Hospital. Her collection, 'Written Portraits', illuminated and contrasted with our other research findings.

Biology, medicine and data records are not the only things that matter to people living and working with cancer.

'Written Portraits' shows what else people liked and different ways that they compared themselves to other people in Maggie's West London, Charing Cross Hospital, and elsewhere.



'Written Portraits' has been used in training and education with undergraduate and graduate students, and with NHS professionals. All materials are available under a CC BY-NC 4.0 license.

“ the best therapy I've had ”  
NHS participant in poetry

## Science Cafés

It is not straightforward to foster productive conversations between scientists, clinicians, patients, and colleagues, even though they may already have met in the hospital, university, and the Maggie's Centre.

Scientists presented to clinicians and patients who had contributed to their research. Students, patients and other people familiarised themselves with the process of commenting and contributing while they considered taking up more formal research roles.

“ like peeking behind the curtain to understand what takes place backstage ”

Science café participant

Science cafés worked as part of a hub and platform - staff and patients were inspired, informed, and felt more confident to exchange ideas and opinions, and join other activities.

Participants in science cafés considered the difficulties for patients and staff as new norms are implemented - the interface between care and research activities is an important area to address.

Poetry and cafés highlighted things that are important to some people but not all – such as the difficulties of being categorised by race, gender or age as well as biological markers.

Kelly Gleason, 2022. '[Reflections on Developing and Running a Science Café at the Cancer Research UK Imperial Centre.](https://www.imperial.ac.uk/patient-experience-research-centre/)' Visit [www.imperial.ac.uk/patient-experience-research-centre/](https://www.imperial.ac.uk/patient-experience-research-centre/).

Sophie Day et al. (Forthcoming.) 'In the Picture': Perspectives on Living and Working With Cancer.'

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