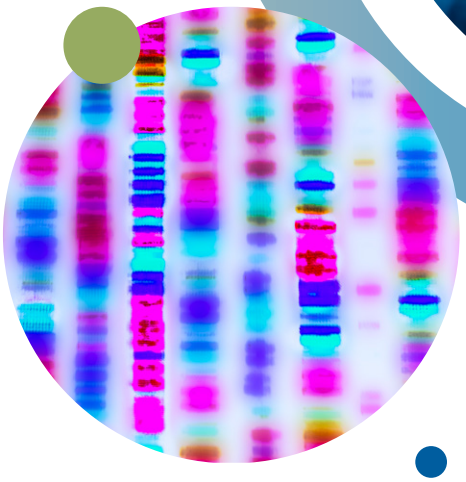
NHS
Wessex
Cancer Alliance

Cancer Genomics Strategy and Work Plan

2023-2026



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1. Background

Genetics = the study of genes; the way certain conditions are passed down through generations

Genomics = the study of a person's genes (the genome).

All cancer is genetic in origin. Cells in the body are dividing all the time. Each time a cell divides, errors might be introduced. While there are many mechanisms within the cell to correct these errors, occasionally they are missed, and this can lead to cancer. We can now use genomic information to inform our approach to cancer, helping to better diagnose, treat and even prevent cancer. Advances in genomic sequencing (looking at the code contained within people's genes) and the interpretation of results mean we are beginning to understand the impact different genes have on cancer development and progression. By comparing the genomes of cancerous and healthy cells, the information can then be used by healthcare professionals to better diagnose, inform prognosis and treat many different cancer types (Cancer Research UK, 2020).

Half of all people born in the United Kingdom after 1960 will be diagnosed with cancer in their lifetime (Ahmad et al, 2015). For many of these, early diagnosis means better prospects for treatment and longer survival. Similarly, delayed treatment can lead to a lower likelihood of survival, greater treatment morbidity, and higher costs of care.

There are two types of genomic information relevant for people with cancer. First, the changes that occur spontaneously (somatic variants) that can cause cancer. Second, the genomic code that they are born with (germline sequence) as this may contain alterations in genes which increase their lifetime risk of cancer (cancer susceptibility genes) (Health Education England, 2023).

The national genomic test directory for cancer specifies the genomic tests commissioned by the NHS in England for cancer, the technology by which they are available, and the patients who will be eligible to access a test. This includes solid, neurological and haematological tumours, sarcoma and paediatric tumours (NHS England, 2023). This test directory is updated on at least an annual basis to ensure that it reflects the rapid pace of development in scientific knowledge, testing technology and evidence of effective impact on patient care. Small numbers of urgent updates can be issued between these annual updates. The impact of these updates varies dramatically. The most recent update in April 2023 resulted in changes to only three adult solid non-CNS cancer types, and meant a fairly small increase in the number of patients requiring genomic testing; the prior update involved a huge expansion of testing.

CASE STUDY:

Colorectal cancer and Lynch syndrome

Molly Singh (not real name) is a woman diagnosed with right-sided cancer of the colon aged 55. All colorectal cancers are eligible for tumour testing. Her initial tumour testing show findings, meaning she is referred to clinical genetics for genomic testing which identify her as having Lynch syndrome. Her chemotherapy is changed to exclude treatments which are ineffective in Lynch syndrome. Lynch syndrome (LS) is a rare condition that can run in families. People affected by LS have a higher risk of developing some types of cancer. Since 2017, National Institute for Health and Care Excellence (NICE DG27 diagnostic pathway) has recommended that all people with colorectal cancer are tested for Lynch syndrome. Since 2020, NICE also recommended testing for Lynch syndrome in people who are diagnosed with endometrial cancer.

Her surgical plan also changes to more extensive bowel surgery which should reduce her risk of future colorectal cancer. She is enrolled in two clinical trials that may change the treatment of her cancer.

Once recovered from her colorectal surgery, she undergoes risk-reducing gynaecological surgery because of the risk of endometrial and ovarian cancers associated with Lynch syndrome.

Family members are invited for predictive testing for Lynch syndrome. Those found to carry it are offered a colonoscopy every 18 months from age 25 as well as gynaecological risk-reducing surgery.

Adapted from HEE (2023a)

2. Key Wessex Cancer Alliance partners for cancer genomics

Genomic Medicine Service

The Central and South (CAS) Genomic Medicine Service combines the CAS Genomic Medicine Service Alliance (GMSA) and Genomic Laboratory Hub (GLH).

CAS GMSA

The CAS GMSA is one of seven regional Alliances across England encompassing the West Midlands, Thames Valley and Wessex regions established to co-ordinate the integration of genomics into the healthcare provided for an increasing number and range of patients who have the potential to benefit. It is the largest GMSA in England, serving 10 million people, 14 Integrated Care Systems (ICSs) and 45 NHS Trusts.

CAS GLH

The CAS GLH is hosted by Birmingham Women's and Children's NHS Foundation Trust, working in partnership with Local Genomic Laboratories (LGLs) in Birmingham, Oxford and Wessex. The Wessex LGL is hosted by University Hospital Southampton NHS Foundation Trust and is known locally as the Wessex Genomics Laboratory Service (WGLS). Sites are at Southampton General Hospital (laboratory formerly known as Molecular Pathology) and Salisbury (formerly the Wessex Regional Genetics Laboratory).The GLH is commissioned to provide all genomic testing across the Central and South region, as set out in the national genomic test directory.

UHS

The CAS partner NHS Trust in Wessex is University Hospital Southampton NHS Foundation Trust (UHS). UHS hosts the tertiary Wessex Clinical Genetics service which is a multidisciplinary team of clinical geneticists, genetic counsellors, specialist nurses, research officers and administrative staff. Clinical Genetics teams work together to diagnose genetic conditions within families and also to help patients to understand and adapt to their conditions. Once an initial genetic diagnosis is made in an individual, other members of their family may be seen by Clinical Genetics to assess their risk of inheriting the condition. UHS also hosts the Wessex LGL as above.

ICSs

Hampshire & Isle of Wight (HIOW) and Dorset Integrated Care Systems (ICS): the Alliance works in partnership with the two ICSs to lead delivery of the cancer elements of the NHS Long Term Plan and to provide strategic leadership and coordination of cancer services across all Wessex.

Health Education England (HEE)

HEE (now subsumed into NHSE): across the South East and South West works with the Alliance to develop workforce plans in relation to both cancer and genomics to provide accelerated, co-ordinated, multi-professional training.

Wessex AHSN

Wessex Academic Health Science Network (AHSN): the Wessex cancer innovation programme was developed to identify and support the adoption of innovations that enable teams across Wessex to diagnose cancers at an early stage.

Universities

The Alliance works in partnership with local universities to develop education and training for genomics

Voluntary sector

Voluntary sector including national, regional and local organisations, work with the Alliance to share insight and outcomes as they provide support for people with cancer via funding services, education and grants

3. What are healthcare staff/provider priorities in relation to cancer genomics?

- Access to timely, high-quality diagnostic, prognostic and predictive tests for patients with all stages of disease, including increasing applications in early detection, diagnosis and even prevention. Such access should be aligned to improvements in patient care and use of healthcare resources.
- Clear guidance on what testing is available, eligibility criteria, how to request it and how long results will take.
- Results made available in a format and with accompanying information that clinical staff can understand and share/explain to patients.
- Access to appropriate training and continuing professional development resources in order to have the knowledge and skills to understand this information, discuss it with patients and keep up-to-date with any new development.
- Optimise use of information for clinical care, research and service evaluation and improvement.
- Access to increased range of molecularly stratified clinical trials (studies where patients are matched to a clinical trial most likely to provide benefit according to the results of their molecular testing) and novel therapies, which are likely to become the expected standard of care.

4. What are patients' priorities in relation to cancer genomics?

- It is important that patients understand the genetic nature of cancer and the relationship between cancer and genomics.
- Early access to information on genomics and early testing where appropriate and according to the national genomic test directory for patients diagnosed with cancer as this may impact their treatment plan (i.e. the type of surgery, timing of surgery, type of treatment e.g. chemotherapy) and prevention of further cancers.
- A streamlined pathway should be established to ensure patients receive the necessary dedicated care required based on all findings from genome sequencing.
- Providing information to family members where appropriate so that they can make their own decisions about testing and potentially access enhanced screening and consider risk reducing interventions.
- Ongoing communication and support from informed healthcare professionals.
- Research studies can benefit from the willingness of patients to contribute to research through sharing their genetic data: communicating to patients the aims of research and how results will be used, could lead to greater involvement of patients in research using genetic data, with greater confidence from patients in the work being undertaken.
- Health data custodians to facilitate as much research as possible while adhering to agreed safeguards (Hastings-Ward et al, 2022; Wipperman & Campos, 2016).

Person with lived experience of genomic testing:

"I was diagnosed with Triple Negative Breast Cancer in 2017. I knew about genomic testing from colleagues and asked at my first appointment with my surgeon for BRCA testing but was told this would be dealt with later in my treatment. I was given no information about the process for testing or implications of BRCA at this time and researched it myself on the internet. I went ahead with surgery and then started a clinical trial which involved initial screening for BRCA. I commenced chemotherapy before the result was returned, six months after my initial diagnosis and I am, in fact, BRCA2 positive.

If the genomic test had been available at the beginning of my treatment, I could have considered different surgical options and potentially a change to my chemotherapy treatment. My family were tested; my eldest daughter is also BRCA2 positive and has been able to choose to have an elective mastectomy and is being monitored prior to proceeding with any further gynaecology surgery and is also participating in a trial relating to this.

I am encouraged to see that efforts are being made to make testing more accessible and for patients to be given literature and guidance as soon as it is possible to obtain genetic counselling and genomics screening. It is important that information given is sensitively handled and existing staff from all areas should be trained on genetic implications and additional specialised staff involved in the initial cancer pathway."

5. What are Wessex Cancer Alliance's priorities in relation to cancer genomics?

The NHS Long Term plan (NHS England, 2019) sets out the following ambitions in relation to cancer genomics:

p.61 3.63.

- We will extend the use of molecular diagnostics and, over the next ten years, the NHS will routinely offer genomic testing to all people with cancer for whom it would be of clinical benefit, and expand participation in research…The NHS will begin from 2020/21 to offer more extensive genomic testing to patients who are newly diagnosed with cancers so that by 2023 over 100,000 people a year can access these tests.

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- Children with cancer, and adults suffering from...specific cancers, will begin to be offered whole genome sequencing.

What have we achieved in Wessex?

We have increased the number of cancer patients who can access whole genome sequencing (a complex and comprehensive diagnostic test looking at the whole genome) (NHS England, 2021).

We have worked to ensure that innovative and effective genomic technologies such as circulating tumour DNA (ctDNA) in stages 3 and 4 lung cancer can be trialled in Wessex to generate evidence about its clinical utility and acceptability to patients with lung cancer.

We have 'mainstreamed' BRCA testing in ovarian cancer across Wessex and in breast cancer in Isle of Wight, Guernsey, Basingstoke and Winchester and are rolling this out across Wessex. Women with mutations in the BRCA1/2 genes have an increased chance of developing breast and ovarian cancer; women with a BRCA1/2 mutation have a 45-65% chance of developing breast cancer by age 70 and a higher breast cancer risk compared with the general population in all age groups. BRCA1 and BRCA2 mutations affect an estimated 0.11% and 0.12% of the general population respectively (around 1 in 450 women) (Cancer Research UK, 2018). 'Mainstreaming' is where the clinical team who know the patient can counsel, consent and give results directly to patients (Bunnik et al, 2021).

We are embedding equitable testing pathways for patients with colorectal and endometrial cancer to be tested for Lynch syndrome across Wessex.

We have established a cancer genomics special interest group (a multidisciplinary group of healthcare professionals across the Wessex region), meeting quarterly. The purpose of the group is to promote and support advances in cancer genomics knowledge and research, sharing best practice and providing education and peer support.

Where do we want to be?

This document uses the NHS four key priority areas as articulated in the NHS England genomic strategy (2022) to identify where we want to be for the population of Wessex in the future:

1. **Embedding genomics in the NHS through a world leading, innovative service**
2. **Delivering equitable genomic testing**
3. **Enabling genomics to be at the forefront of the data and digital revolution**
4. **Evolving the service through cutting-edge science, research and innovation**

This document sets out the actions related to the four key priority areas which aim to make these ambitions a reality for people at risk of cancer or living with and beyond cancer and their families in Wessex.

This document aligns with the Wessex Cancer Alliance strategic plan 'Our Cancer Plan for Wessex' 2019-2024 (Wessex Cancer Alliance, 2019).

Priority One

Wessex Cancer Alliance will work with key Alliance partners to embed genomics into cancer care across Wessex from primary and community care through to specialist and tertiary care.

Wessex Cancer Alliance will work with the public, participants in genomic research and patients in addition to key Alliance partners to:

- Create world-leading innovative service models for cancer genomics, that matter to the public, participants in genomic research and patients and make a difference to their lives.
- With the Alliance equality lead, work towards equity of access to genomic testing for all people, particularly areas of deprivation where need is often highest and access lowest.
- Influence the development of sustainable high quality infrastructures across testing, clinical services and research and innovation.
- Ensure public, participant and patient voices are embedded throughout decision making, to ensure that new technological and clinical processes are met with trust.
- Build greater clinical and professional leadership and develop the capacity and capability of the workforce with partners.
- Support the alignment of the NHS GMS with Integrated Care Systems, NHSE Pathology Networks and the provision of expert advice with regards to cancer genomics service provision and delivery.
- Recognise that 'one size does not fit all', tailoring communication regarding cancer genomics sensitively and appropriately to participant communities, following best practice in genomics communication as outlined by the independent Participant Panel at Genomics England (Genomics England Participant Panel, 2022).
- Ensure that mainstreaming of genomic testing and care is an integral part of clinical nurse specialist job plans.

Priority Two

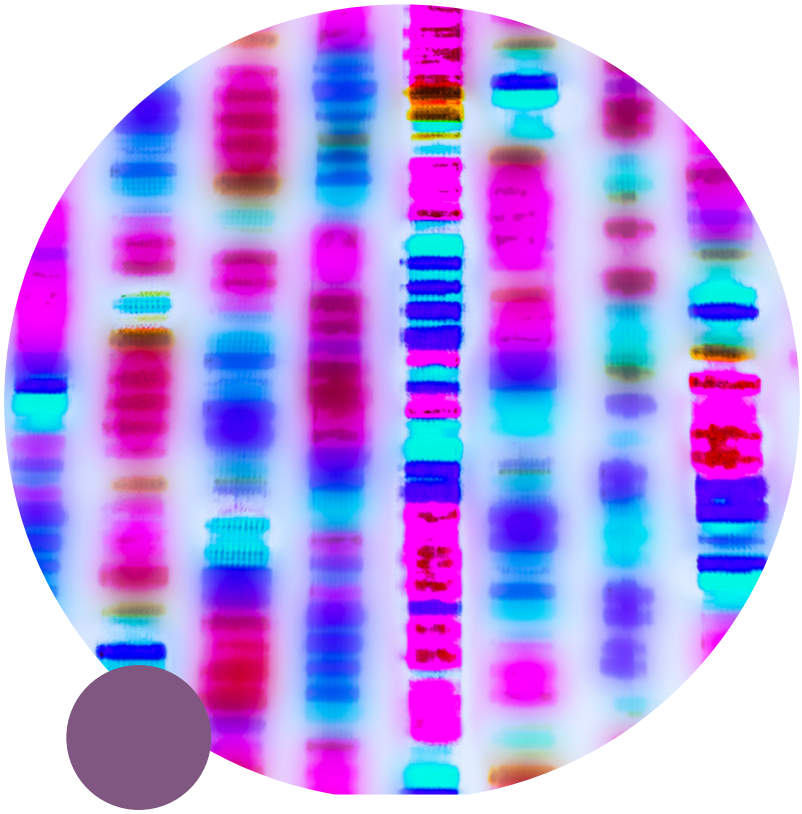
Wessex Cancer Alliance will work with key Alliance partners to deliver equitable genomic testing for improved outcomes in cancer, enabling precision medicine and reducing adverse drug reactions through:

- Redesigning pathways to ensure the timely availability of genomic test results to inform clinical care and decision making (e.g. the collection of biopsies for cancer genomics early in the diagnosis pathway).
- The delivery of rapid turnaround times for certain types of cancer where results are needed urgently to inform diagnosis and treatment.
- The exploration of how useful genomic testing might be to support population screening for cancer (e.g. reviewing the evidence from population based studies to detect cancer earlier, such as the research trial of the GRAIL Galleri test, and piloting the expansion of BRCA testing in higher risk populations).
- The exploration of opportunities to increase cancer genomic testing referrals from primary and community care where clinically appropriate.
- The monitoring of activity data and turnaround times for cancer genomic testing.
- Ensuring equity of access to the nationally commissioned genomic tests set out in the national genomic test directory so that all people with cancer in Wessex who could benefit from genomic testing are able to do so, no matter where they live or which hospital they use.
- The enabling and support for oncology clinicians to request genomic tests directly ('mainstreaming').
- Developing and equipping the current and future Wessex workforce with the skills and knowledge to deliver genomics medicine, including enabling discussions with patients and their families through evidence-based education and training.
- Attracting and retaining the specialist workforce (e.g. clinical scientists) which is often limited in numbers, in ways that support increased testing volumes, timely results, and an efficient and high quality service.

Priority Three

Wessex Cancer Alliance will work with key Alliance partners to enable genomics to be at the forefront of the data and digital revolution, ensuring genomic data can be effectively interpreted and considered alongside other diagnostic and clinical data.

- Design, pilot and iterate new operating models for cancer involving multiple genomic testing approaches.
- Working with Genomics England and the Cancer 2.0 programme (Genomics England, 2023) to ensure multidisciplinary teams can draw on multimodal data across imaging, genomics and longitudinal health and care data.
- Prevent and identify cancer earlier by harnessing emerging genomics technologies including long-read sequencing, circulating tumour DNA, and RNA sequencing.
- Work with NHSE Secure Data Environment programs to support secure access to cancer genomic data, to improve therapeutic opportunities (i.e. clinical trial eligibility).



Priority Four

Wessex Cancer Alliance will work with key Alliance partners to evolve the service through cutting-edge science, research and innovation to ensure that patients can benefit from rapid implementation of advances in genomic testing.

- Work with the Wessex Clinical Research Network to ensure that there is equitable access to opportunities to participate in clinical trials informed by genomic data commitments.
- Work with the Wessex Clinical Research Network to ensure the effective implementation of Find, Recruit and Follow-up (FRF) programme which aims to harness the potential of health data and digital tools to support effective, efficient trial delivery and wider participation in research across the UK (as outlined in The Future of UK Clinical Research Delivery and its associated implementation plan) (Department of Health and Social Care, 2021)
- Work with University Hospital Southampton NHS Foundation Trust to lead on the Cancer Vaccine Launch Pad (CVLP) in Wessex.

  Support UHSFT to report key metrics to NHSE and share learning. The CVLP is designed to act as a bridge to enable NHS cancer patients to get the earliest possible access to personalised cancer vaccine trials. Personalised cancer vaccines are a type of cancer treatment designed to target the specific molecular changes in an individual's cancer cells. They are created by analysing a patient's tumour and identifying specific mutations that are unique to that cancer, then using that information to create a vaccine tailored to that patient. The intention is that the vaccine will stimulate the immune system to specifically recognise and destroy the cancer cells.
- In future phases, support the set-up of new sites in Wessex as the CVLP is scaled up to additional Trusts and cancer types.

6. Wessex Cancer Alliance actions planned July 2023 - December 2026

2023-2024

- Fund sessional time for a general practitioner (GP) with experience in cancer and genomics to work Wessex wide, leading the primary care genomics agenda in Wessex.
- Fund a Wessex wide genomics transformation post to support the embedding of cancer genomics as business as usual within Wessex, including the development of a sustainable commissioning model.
- Fund and support a Wessex wide Lynch lead (genetics counsellor) and Wessex wide Lynch support (genomics associate).
- Fund and support immunohistochemistry pathway coordinators in each of the cellular pathology departments in each of our Wessex Trusts, providing a peer support group.
- Fund and support clinical nurse specialist time to dedicate to 'mainstreaming' Lynch testing in each of our Wessex Trusts, providing a peer support group.
- Identify and support Lynch champions in every colorectal and gynaecological multidisciplinary team at each of our Wessex Trusts, including ensuring the appropriate training of Lynch champions.
- Undertake audits of the Lynch pathway in each of our Wessex Trusts to identify and address any gaps in the pathway.
- Fund and support Wessex wide consultant genetic counsellor to lead 'mainstreaming' education and provide virtual 'mainstreaming' clinics for BRCA.
- Funding and support for BRCA training and educational materials (e.g. videos and leaflets) hosted on the Wessex Cancer Alliance website.
- Fund and support lead children's cancer nurse at the principal treatment centre to champion whole genome sequencing.
- Service improvement support for a nurse-led cross organisational multidisciplinary working group to develop pathways for the implementation of whole genome sequencing.
- Funding for a Genomics Tumour Advisory Board (GTAB) coordinator (a GTAB is a panel of clinical experts to provide advice regarding the analysis of patients' tumour/germline genomic data to inform clinical care) (for whole genome sequencing discussion).
- Develop and maintain the content of cancer genomics for the Wessex Cancer Alliance website.

2023-2026

- Work with key Alliance partners to continue to raise awareness of cancer genomics, including the benefits and challenges, supporting ongoing and transparent public dialogue on issues relating to genomics.
- Work with the NHS GMS Ethics Advisory Board, the GMS and other partners to consider the introduction of new technologies, return of results, data protection and genomic research, among other areas.
- Work with the lived experience expertise of the Wessex Cancer Alliance patient experience group to ensure that communication regarding cancer genomics is tailored sensitively and appropriately to participant communities.
- Work with key Alliance partners to ensure that the diagnostic infrastructure for genomic testing in the NHS is appropriately resourced and supported, both in terms of finance and staffing.
- Work with key Alliance partners to deliver the upskilling of the workforce and drive the change in practice needed for the embedding of genomics in the NHS, including through the Academy of Medical Royal Colleges Multi-professional Genomics Partnership Group and through working with specific professional groups, including pharmacists, nurses and midwives (see Wessex Cancer Alliance cancer workforce strategy (Wessex Cancer Alliance, 2022).
- Work with key Alliance partners to embed ovarian 'mainstreaming' pathway and 'mainstreaming' the breast pathway for patients with mutations in the BRCA1/2 genes (which result in an increased chance of developing breast and ovarian cancer).
- Working with providers to support the development of a dedicated workforce for delivering the BRCA agenda.
- Work with key Alliance partners to ensure equitable access to whole genome sequencing. As per national priorities, the initial focus will be on children with cancer and patients of any age with sarcoma and leukaemia.
- Work with key Alliance partners and the Dorset Information and Intelligence Service (DiiS) to ensure that the Alliance approach to cancer genomics is driven by contemporaneous and accurate data.
- Wessex Cancer Alliance has worked with clinical teams to identify and support a Wessex wide cancer genomics specialist interest group. Its inaugural meeting was held in 2022. Wessex Cancer Alliance will continue to provide administrative support to this group and ensure that outcomes from the group inform the strategic and operational direction of cancer genomics in Wessex.
- Work with NHS England to support the testing and use of the Galleri genomic test for cancer. This will include careful evaluation of staff and patient experience, in addition to clinical utility.
- Support the testing of the effectiveness of innovative and effective genomic technologies, such as circulating tumour DNA (ctDNA).

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