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| **Nombre** | **N.º del NHS** (o código postal, si no se conoce) | | | | | | | | | | | | | | | | | |
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| **Apellidos** |  | | | **Fecha de nacimiento** | | | | | | | | | | | | | | |
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# Record of Discussion Regarding Genomic Testing

# Registro de conversación sobre la prueba genómica

***This form relates to the person being tested. One form is required for each person.***

*All of the statements below remain relevant even if the test relates to someone other than yourself, for example your child.*

***Este formulario se refiere a la persona a la que se realizará la prueba. Se necesitará un formulario por persona.***

*Todas las declaraciones que constan a continuación son relevantes, incluso si la prueba se refiere a otra persona, por ejemplo, a su hijo/a.*

**I have discussed genomic testing with my health professional and understand the following**

**He hablado de la prueba genómica con mi médico y comprendo la siguiente información**

## Family and wider implications

1. The results of my test may have implications for me and members of my family. I understand that my results may also be used to help the healthcare of members of my family and others nationally and internationally. This could be done in discussion with me or through a process that will not personally identify me.

## Familia e implicaciones más amplias

1. Los resultados de mi prueba pueden tener implicaciones tanto para mí, como para los miembros de mi familia. Comprendo que los resultados también se podrán utilizar para la atención médica de miembros de mi familia y de otras personas, tanto de este país como de otros. Esto se llevaría a cabo después de hablarlo conmigo o mediante un proceso que no permita que se me identifique personalmente.

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## Uncertainty

1. The results of my test may have findings that are uncertain and not yet fully understood. To decide whether findings are significant for myself or others, my data may be compared to other patients’ results across the country and internationally. I understand that this could change what my results mean for me and my treatment over time.

## Certeza

2. Los resultados de mi prueba pueden incluir información que no esté clara o aún no se comprenda del todo. A fin de decidir si los hallazgos son significativos para mí o para otras personas, mis datos podrán compararse con los resultados de otros pacientes del Reino Unido o de otros países. Comprendo que esto podría cambiar lo que estos resultados significan para mí, así como mi tratamiento con el tiempo.

## Unexpected information

1. The results of my test may also reveal unexpected results that are not related to why I am having this test. These may be found by chance and I may need further tests or investigations to understand their significance.

## Información inesperada

3. Los resultados de mi prueba también podrán arrojar información inesperada no relacionada con los motivos por los que se realiza. Esta información podría hallarse por casualidad, y puede ser que necesite someterme a más pruebas o investigaciones que permitan determinar su significado.

## DNA storage

1. Normal NHS laboratory practice is to store the DNA extracted from my sample even after my current testing is complete. My DNA might be used for future analysis and/or to ensure that other testing (for example that of family members) is of high quality.

## Almacenamiento del ADN

1. La práctica de laboratorio normal del NHS consiste en almacenar el ADN extraído de mi muestra, incluso una vez finalizada la prueba. Mi ADN podrá ser utilizado para análisis posteriores y para garantizar que otras pruebas (por ejemplo, las realizadas a otros miembros de la familia) son de alta calidad.

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***Data storage***

1. The data from my genomic test will be securely stored so that it can be looked at again in the future if necessary.

***Almacenamiento de datos***

1. Los datos de mi prueba genómica se almacenarán de forma segura, de forma que puedan consultarse de nuevo en el futuro si fuera necesario.

## Health records

6. Results from my genomic test will be part of my patient record, a copy of which is held in a national system only available to healthcare professionals.

## Historia clínica

6. Los resultados de mi prueba genómica formarán parte de mi historia clínica, una copia de los cuales se encuentran en un sistema nacional únicamente disponible para los profesionales sanitarios.

## Research

7. I understand that I have the opportunity to take part in research which may benefit myself or others, now or in the future. An offer to join a national research opportunity is available on the following page.

## Investigación

7. Comprendo que tengo la oportunidad de participar en una investigación que me podría beneficiar tanto a mí, como a otras personas, ahora o en el futuro. La siguiente página incluye una oferta para participar en una investigación nacional.

For any further questions, my healthcare professional can provide information. More information regarding genomic testing and how my data is protected can be found [at www.nhs.uk/conditions/genetics](https://www.nhs.uk/conditions/genetics/)

Su médico podrá responderle a cualquier duda o pregunta que tenga. Para consultar más información sobre las pruebas genómicas y la protección de sus datos, consulte  [www.nhs.uk/conditions/genetics](https://www.nhs.uk/conditions/genetics/)

**Please sign on page seven to confirm your agreement to the genomic test.**

**Firme la página 7 para ratificar su consentimiento para participar en la prueba genómica.**

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# The National Genomic Research Library

# Biblioteca Nacional de Investigación Genómica

**The NHS invites you to contribute to the National Genomic Research Library, managed by Genomics England.**

Genomics England was set up in 2013 by the Department of Health and Social Care to work with the NHS to build a library of human genomes for researchers to study. Combining data from many different patients helps researchers to better understand disease and spot patterns in the data.

By agreeing to share your data you might get results which could lead to your own diagnosis, a new treatment, or offers to take part in clinical trials. Your taking part could enable diagnoses for people who don’t have one.

Please read the following statements. Feel free to ask any questions before making a decision.

**El NHS le invita a contribuir a la Biblioteca Nacional de Investigación Genómica (National Genomic Research Library), gestionada por Genomics England.**

Genomics England fue fundada en 2013 por el Ministerio de Sanidad y Asistencia Social británico para crear junto al NHS una biblioteca del genoma humano dedicada a la investigación. La combinación de datos de diversos pacientes ayuda a los investigadores a comprender mejor las enfermedades y a identificar patrones en los datos.

Al acceder a compartir sus datos, obtendrá resultados que podrían ayudar a su diagnóstico, a un nuevo tratamiento u ofertas para participar en ensayos clínicos. Su participación podría ser útil para el diagnóstico de otras personas.

Lea las siguientes declaraciones. Antes de tomar una decisión, haga todas las preguntas que considere necesarias.

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**By saying ‘yes’ to research, I understand the following**

**Al marcar la opción "Sí", soy consciente de lo siguiente**

## The National Genomic Research Library

1. NHS England, on behalf of the Trusts that provided your genomic test, will allow Genomics England to access my personal data including my genomic record.

## Biblioteca Nacional de Investigación Genómica

1. NHS England, en nombre de los Trusts que han facilitado su prueba genómica, permitirá a Genomics England acceder a mis datos personales, incluido mi registro genómico.

## Security

1. Any samples and data stored by Genomics England and the NHS will always be stored securely. Genomics England will take all reasonable steps to ensure that I cannot be personally identified.

## Seguridad

2. Todas las muestras y los datos almacenados por Genomics England y el NHS se guardarán siempre de una manera segura. Genomics England adoptará todas las medidas razonables que garanticen que no se me puede identificar personalmente.

## Re-contact

1. My clinical team or Genomics England together with my clinical team, can contact me if the data or samples reveals any clinical trials or other research that I might benefit from.
2. If something is relevant to me or my family, there is a process by which this will be shared with my NHS clinical team.

## Contacto posterior

1. Mi equipo médico, o Genomics England junto con mi equipo médico podrán ponerse en contacto conmigo si los datos o las muestras revelan que existen ensayos clínicos u otras investigaciones de la que me podría beneficiar.
2. Existe un proceso por el cual, si alguna cuestión resultara relevante para mí o para mi familia, se compartirá con mi equipo médico del NHS.

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## Data and sample usage

1. Researchers may include national or international scientists, healthcare companies and NHS staff. To access the data, these researchers must all be approved by an independent committee of experts, including health professionals, clinical academics and patients. There will be no access to the data by personal insurers and marketing companies.

## Uso de los datos y la muestra

5. Los investigadores podrán ser científicos del Reino Unido o de otros países, empresas del sector sanitario y personal del NHS. Para acceder a los datos, estos investigadores deberán haber sido autorizados por un comité de expertos independiente, que incluirá profesionales sanitarios, académicos clínicos y pacientes. Las compañías de seguros personales y de marketing no tendrán acceso a los datos.

## Data storage

1. Genomics England will collect different aspects of my health data from the NHS and other data from organisations listed a[t https://www.genomicsengland.co.uk/privacy-policy/](https://www.genomicsengland.co.uk/understanding-genomics/data). The collection and analysis of my health data for research will continue across my entire lifetime and beyond.

## Almacenamiento de datos

6. Genomics England recopilará distintas cuestiones relativas a mis datos médicos del NHS y de organizaciones enumeradas e [n https://www.genomicsengland.co.uk/privacy-policy/](https://www.genomicsengland.co.uk/understanding-genomics/data). La recogida y análisis de mis datos médicos continuará durante toda mi vida y posteriormente.

## Withdrawal

7. I can change my mind about taking part at any time.

More information regarding research in the National Genomic Research Library can be found at [www.genomicsengland.co.uk](http://www.genomicsengland.co.uk/) For any further questions, my healthcare professional can provide information.

## Retirada

7. Podré decidir no participar en cualquier momento.

Para más información sobre la investigación en la Biblioteca Nacional de Investigación Genómica, consulte [www.genomicsengland.co.uk](http://www.genomicsengland.co.uk/) Su médico podrá proporcionarle información sobre cualquier pregunta adicional.

**Please use page seven to indicate your research choices.**

**Indique en la página 7 sus decisiones relativas a la investigación.**

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# Confirmation of Your Genomic Test and Research Choices

# Confirmación de sus decisiones sobre las pruebas genómicas y las opciones de investigación

**I confirm that I have had the opportunity to discuss information about genomic testing, I agree to the genomic test, and my research choice is indicated below.**

**Confirmo que he tenido la oportunidad de hablar sobre la información acerca de las pruebas genómicas, accedo a someterme a una prueba genómica y mi decisión sobre la investigación se señala a continuación.**

1. **I have discussed taking part in the National Genomic Research Library YES | NO**

*If your answer to A is* **NO** *then please ignore B and sign directly below*

1. **He podido hablar sobre mi participación en la Biblioteca Nacional de Investigación Genómica SÍ | NO**

*Si su respuesta a A es* **NO***, ignore el punto B y firme a continuación.*

1. **I agree that my data and remainder sample may contribute to the National Genomic YES | NO Research Library**
2. **Acepto que mis datos y el resto de mi muestra contribuya a la Biblioteca Nacional de Investigación Genómica SÍ | NO**

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**If you are signing this form on behalf of someone else (children, adults without capacity or deceased patients) then please sign below.**

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| **Parent | Guardian | Consultee name\*** *\**  *please amend as appropriate* | **Signature** | **Date** | |
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| **Nombre del paciente Firma Fecha**   |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | |  | |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | |  |  |  |  |  |  |  |  | | |

**Si firma este formulario en nombre de otra persona (niños, adultos sin capacidad para hacerlo o pacientes difuntos) firme a continuación.**

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| **Padre/madre | Tutor/a | Nombre de la persona consultada\*** *\**  *Modificar según corresponda* | **Firma** | **Fecha** | |
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Healthcare professional use only

To be completed by the healthcare professional recording the patient’s choices.

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| **Patient category** | Adult (made their own choices)  Adult lacking capacity (choices advised by consultee)  Child (parent or guardian choices) | Clinician has agreed to the test (in the patient's best interests)  Deceased (choices made on behalf of deceased individual) |
| **Test type** | Rare and Inherited Diseases - WGS | Cancer (paired tumour normal) - WGS |
| **If answer to research choice A is *NO*** | Patient would like to discuss at a later date  Patient lacks capacity and no consultee available | Inappropriate to have discussion  Other |
| **Remote consent** | Recorded remotely by clinician, no patient signature | |
| **Responsible clinician** |  | |
| **Hospital number** |  | |

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| Healthcare professional name | Signature | Date |
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Para uso exclusivo del profesional sanitario

Debe ser completado por el profesional sanitario que registre las opciones del paciente.

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| **Categoría de paciente** | Adulto (decide por sí mismo/a)  Adultos sin la capacidad para tomar sus propias decisiones (opciones recomendadas por la persona consultada)  Menor (decisión de los padres o los tutores) | El médico ha accedido a realizar la prueba (opción más beneficiosa para el paciente)  Persona difunta (decisión tomada en nombre de una persona difunta) |
| **Tipo de prueba** | Enfermedades raras y hereditarias: secuenciación del genoma completo | Cáncer (tumor asociado normal): secuenciación del genoma completo |
| **Si la respuesta a la decisión sobre la investigación A es *NO*** | El paciente prefiere tratar el asunto más adelante  El paciente no tiene la capacidad para tomar sus propias decisiones y no hay otra persona disponible a la que consultar | No procede mantener la conversación  Otros |
| **Consentimiento remoto** | Registrado a distancia por el médico, sin la firma del paciente | |
| **Médico responsable** |  | |
| **Número de hospital** |  | |

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| Nombre del profesional sanitario | Firma | Fecha |
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