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| **Nome próprio** | **Número do NHS**  (ou código postal, se desconhecido) | | | | | | | | | | | | | | | | | |
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| **Apelido** |  | | | **Data de nascimento** | | | | | | | | | | | | | | |
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# Record of Discussion Regarding Genomic Testing

# Registo das Discussões acerca dos Testes Genómicos

***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.*

***O presente formulário refere-se à pessoa que está a ser testada. É necessário um formulário para cada pessoa.***

*Todas as declarações abaixo permanecem relevantes mesmo que o teste diga respeito a outra pessoa que não o próprio, por exemplo o seu filho.*

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

**Conversei sobre os testes genómicos com o meu profissional de saúde e compreendi o seguinte**

## 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.

## Família e implicações mais amplas

1. Os resultados do meu teste podem ter implicações para mim e para os membros da minha família. Compreendo que os meus resultados também podem ser utilizados para ajudar os cuidados de saúde dos membros da minha família e outros a nível nacional e internacional. Isto poderia ser feito numa conversa comigo ou através de um processo que não me identifique pessoalmente.

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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.

## Incerteza

2. Os resultados do meu teste podem ter resultados inconclusivos e ainda não totalmente compreendidos. Para decidir se os resultados são significativos para mim ou para outros, os meus dados podem ser comparados com os resultados de outros pacientes em todo o país e internacionalmente. Compreendo que tal poderia mudar o que os meus resultados significam para mim e para o meu tratamento ao longo do tempo.

## 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.

## Informação inesperada

3. Os resultados do meu teste também podem revelar resultados inesperados que não estão relacionados com a razão pela qual estou a fazer este teste. Estes podem ser encontrados por acaso e posso necessitar de mais testes ou investigações para compreender o seu 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.

## Armazenamento do ADN

1. A prática normal do laboratório do NHS é armazenar o ADN extraído da minha amostra, mesmo depois de os meus testes atuais estarem concluídos. O meu ADN pode ser utilizado para análises futuras e/ou para assegurar que outros testes (por exemplo, os dos membros da família) sejam de alta qualidade.

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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.

***Data de armazenamento***

1. Os dados do meu teste genómico serão armazenados em segurança para que possam ser novamente analisados no futuro, se necessário.

## 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.

## Registos de saúde

6. Os resultados do meu teste genómico farão parte do meu registo de paciente, uma cópia do qual é mantida num sistema nacional apenas disponível para os profissionais de saúde.

## 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.

## Investigação

7. Compreendo que tenho a oportunidade de participar na investigação que pode beneficiar a mim ou a outras pessoas, agora ou no futuro. Uma possibilidade de adesão a uma oportunidade nacional de investigação está disponível na página seguinte.

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/)

Para quaisquer outras questões, o meu profissional de saúde pode fornecer informações. Mais informações sobre testes genómicos e como os meus dados são protegidos podem ser encontradas [em www.nhs.uk/conditions/genetics](https://www.nhs.uk/conditions/genetics/)

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

**Assine na página sete de modo a confirmar que concorda com o teste genómico.**

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# The National Genomic Research Library

# National Genomic Research Library (Biblioteca Nacional de Investigação 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.

**O NHS convida-o a contribuir para a National Genomic Research Library, gerida pela Genomics England.**

A Genomics England foi criada em 2013 pelo Departamento de Saúde e Assistência Social para trabalhar com o NHS na construção de uma biblioteca de genomas humanos destinada ao estudo de investigadores. A combinação de dados de muitos pacientes diferentes ajuda os investigadores a compreender melhor a doença e os padrões dos pontos nos dados.

Ao concordar em partilhar os seus dados, poderá obter resultados que poderão levar ao seu próprio diagnóstico, a um novo tratamento, ou a ofertas para participar em ensaios clínicos. A sua participação poderia permitir diagnósticos para pessoas que não os têm.

Leia as seguintes afirmações. Sinta-se à vontade para fazer quaisquer perguntas antes de tomar uma decisão.

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

**Ao dizer "sim" à investigação, compreendo o seguinte**

## 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.

## National Genomic Research Library (Biblioteca Nacional de Investigação Genómica)

1. O NHS de Inglaterra, em nome dos Trusts que disponibilizaram o seu teste genómico, permitirá à Genomics England aceder aos meus dados pessoais, incluindo o meu registo 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.

## Segurança

2. Quaisquer amostras e dados armazenados pela Genomics England e o NHS serão sempre armazenados em segurança. A Genomics England tomará todas as medidas razoáveis para garantir que não posso ser pessoalmente identificado.

## 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.

## Novo contacto

1. A minha equipa clínica ou Genomics England, juntamente com a minha equipa clínica, podem contactar-me se os dados ou amostras revelarem quaisquer ensaios clínicos ou outra investigação de que eu possa beneficiar.
2. Se algo é relevante para mim ou para a minha família, há um processo pelo qual isto será partilhado com a minha equipa clínica do SNS.

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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.

## Utilização de dados e amostras

5. Os investigadores podem incluir cientistas nacionais ou internacionais, empresas de saúde e pessoal do NHS. Para aceder aos dados, todos estes investigadores devem ser aprovados por um comité independente de peritos, incluindo profissionais de saúde, académicos clínicos e pacientes. Não haverá acesso aos dados por parte das seguradoras pessoais e empresas de marketing.

## 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/understanding-genomics/data) <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.

## Data de armazenamento

6. A Genomics England recolherá diferentes aspetos dos meus dados de saúde do NHS e outros dados de organizações enumeradas em [https://www.genomicsengland.co.uk/privacy-policy](https://www.genomicsengland.co.uk/understanding-genomics/data)/. A recolha e análise dos meus dados de saúde para investigação continuará ao longo de toda a minha vida e para além dela.

## 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.

## Desistência

7. Posso mudar de ideias sobre a minha participação em qualquer altura.   
Mais informações sobre investigação na National Genomic Research Library (Biblioteca Nacional de   
Investigação Genómica) podem ser encontradas em [www.genomicsengland.co.uk](http://www.genomicsengland.co.uk/) Para quaisquer outras   
questões, o meu profissional de saúde pode fornecer informações.

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

**Utilize a página sete para indicar as suas escolhas de investigação.**

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# Confirmation of Your Genomic Test and Research Choices

# Confirmação do seu teste genómico e escolhas de investigação

**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 tive a oportunidade de discutir informações sobre testes genómicos, concordo com o teste genómico e a minha escolha de investigação é indicada abaixo.**

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. **Discuti a minha participação na National Genomic Research Library SIM | NÃO**

*Se a sua resposta a A for* **NÃO***, ignore B e assine diretamente abaixo*

1. **I agree that my data and remainder sample may contribute to the National Genomic YES | NO Research Library**
2. **Concordo que os meus dados e a amostra restante podem contribuir para a National Genomic Biblioteca de Investigação SIM | NÃO**

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| **Patient name Signature Date**   |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | |  | |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | |  |  |  |  |  |  |  |  | | |

**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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| **Nome do paciente Assinatura Data**   |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | |  | |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | |  |  |  |  |  |  |  |  | | |

**Se está a assinar este formulário em nome de outra pessoa (crianças, adultos incapacitados ou pessoas falecidas), assine abaixo.**

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| **Pai | Tutor | Consulte o nome\*** *\**  *alterar conforme apropriado* | **Assinatura** | **Data** |  |  |  |  |  |  | |
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Healthcare professional use only

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

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| Healthcare professional name | Signature | Date |
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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** |  | |

Utilização apenas por profissionais de saúde

A ser preenchido pelo profissional de saúde que regista as escolhas do paciente.

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| **Categoria do paciente** | Adulto (fez as suas próprias escolhas)  Adulto com incapacidade (escolhas aconselhadas pelo consultor)  Criança (escolha dos pais ou tutores) | O médico concordou com o teste (no melhor interesse do paciente)  Falecido (escolhas feitas em nome de um indivíduo falecido) |
| **Topo de teste** | Doenças Raras e Hereditárias - WGS | Cancro (tumor emparelhado normal) - WGS |
| **Se a resposta à opção de investigação A for *NÃO*** | O paciente desejaria conversar em data posterior  Incapacidade do paciente e não existe consulta disponível | Inadequado para ter uma conversa  Outra opção |
| **Consentimento remoto** | Registado remotamente pelo médico, sem a assinatura do paciente | |
| **Médico responsável** |  | |
| **Número do Hospital** |  | |

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| Nome do profissional de saúde | Assinatura | Data |
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