

First name	NHS number (or postcode if not known)
Last name	Date of birth

名字	NHS 编号 (若不清楚, 则填写邮政编码)
姓氏	出生日期

Record of Discussion Regarding Genomic Testing

基因组检测讨论记录

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.

此表格针对受测个人。每人需要使用一份表格。

即使检测针对的是您以外的其他人 (例如您的孩子), 以下所有陈述仍然相关。

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

我已经与我的医疗保健专业人员讨论过基因组检测并理解以下内容

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.

对家人及更大范围的影响

1. 我的检测结果可能会对我和我的家人产生影响。我知道我的结果也可用于帮助为我的家人以及全国范围和国际上的其他人提供医疗保健服务。这可以通过与我进行讨论或通过一个不会识别我个人身份的流程来实现。



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Uncertainty

2. 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.

不确定性

2. 我的检测结果可能会揭示不确定且尚未完全理解的发现。为了确定这些发现对我自己或其他人是否有意义，我的数据可能会与全国和国际其他患者的结果进行比较。我知道随着时间的推移，这可能会改变我的结果对我和我的治疗的意义。

Unexpected information

3. 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.

意外信息

3. 我的检测结果也可能会揭示与我进行此检测的原因无关的意外结果。这可能是偶然发现的，我可能需要进行进一步的检测或调查才能了解其意义。

DNA storage

4. 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.

DNA 储存

4. 常规的 NHS 实验室做法是储存从我的样本中提取的 DNA，即使在我当前的检测已完成后也是如此。我的 DNA 可能用于未来的分析和/或用于确保其他检测（例如，对我家人的检测）具有高质量。



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Data storage

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

数据存储

5. 从我的基因组检测得到的数据将安全存储，以便将来必要时再次查看。

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.

健康记录

6. 我的基因组检测结果将录入我的患者记录，患者记录副本保存在仅供医疗保健专业人员访问的国家系统中。

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.

研究

7. 我明白，我有机会参与可能会在现在或将来使我自己或他人受益的研究。关于加入国家研究的提议载于下一页。

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

如果我还有任何其他问题，我的医疗保健专业人员可以提供信息。有关基因组检测以及如何保护我的数据的更多信息，可访问 www.nhs.uk/conditions/genetics

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

请在第七页签名以确认您同意进行基因组检测。



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The National Genomic Research Library

国家基因组研究库

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.

NHS 邀请您为由 Genomics England 管理的国家基因组研究库进行捐献。

Genomics England 于 2013 年由卫生及社会关怀部成立，旨在与 NHS 合作建立人类基因组库供研究人员进行研究。汇总来自大量不同患者的数据，将有助于研究人员更好地了解疾病并发现数据中的规律。

通过同意分享您的数据，您可能会获得结果，这些结果可能会使您的病症得到诊断、为您提供新的治疗选择，或让您有机会参与临床试验。您的参与可能会让未得到诊断的患者得到诊断。

请阅读以下声明。在做出决定之前，请随意提出任何问题。



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By saying 'yes' to research, I understand the following

如果我对加入研究回答“是”，即表示我理解以下内容

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.

国家基因组研究库

1. 英国 NHS 将代表为我提供基因组检测的信托机构，允许 Genomics England 访问我的个人数据，包括我的基因组记录。

Security

2. 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.

安全

2. Genomics England 和 NHS 储存的任何样本和数据将始终予以安全储存。Genomics England 将采取一切合理措施确保我的个人身份不会被识别。

Re-contact

3. 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.
4. If something is relevant to me or my family, there is a process by which this will be shared with my NHS clinical team.

再联系

3. 如果数据或样本表明我可能受益于任何临床试验或其他研究，我的临床团队可以联系我，或者 Genomics England 可以与我的临床团队一起联系我。
4. 如果发现与我或我的家人有关的情况，将通过相应的流程通知我的 NHS 临床团队。

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Data and sample usage

5. 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.

数据和样本使用

5. 研究人员可能包括国内或国际科学家、医疗保健公司和 NHS 工作人员。所有这些研究人员均必须得到独立专家（包括医疗保健专业人员、临床学者和患者）委员会的批准才能访问数据。个人保险公司和销售公司将无法访问这些数据。

Data storage

6. Genomics England will collect different aspects of my health data from the NHS and other data from organisations listed at <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.

数据存储

6. Genomics England 将从 NHS 收集我的各种健康数据以及来自 <https://www.genomicsengland.co.uk/understanding-genomics/data/> 上列出的组织的其他数据。出于研究目的的收集和分析我的健康数据，将在我的一生中及以后持续进行。

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 For any further questions, my healthcare professional can provide information.

退出

7. 我可以随时改变主意，决定不再参加。

有关国家基因组研究库研究的更多信息，可访问 www.genomicsengland.co.uk。如果我还有任何其他问题，我的医疗保健专业人员可以提供信息。

Please use page seven to indicate your research choices.

请在第七页表明您的研究选择。



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Confirmation of Your Genomic Test and Research Choices

确认您的基因组检测和研究选择

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.

我确认，我已有机会讨论有关基因组检测的信息，我同意进行基因组检测，并且我在下面表明了研究选择。

A. 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

A. 我已讨论过加入国家基因组研究库一事 是 | 否
如果您对 A 的回答是“否”，那么请忽略 B 并直接在下面签名

B. I agree that my data and remainder sample may contribute to the National Genomic Research Library YES | NO

B. 我同意可将我的数据和剩余样本捐献给国家基因组研究库 是 | 否

Patient name	Signature	Date										
		<table border="1"><tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>										

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

Parent Guardian Consultee name*	Signature	Date										
<i>please amend as appropriate</i>		<table border="1"><tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>										

患者姓名	签名	日期										
		<table border="1"><tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>										

如果您代表其他人（儿童、无行为能力的成人或已故患者）签署此表格，请在下方签名。

父母 监护人 求询者姓名*	签名	日期										
<i>请酌情修改</i>		<table border="1"><tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>										



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Healthcare professional use only

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

Patient category	Adult (made their own choices)	Clinician has agreed to the test (in the patient's best interests)
	Adult lacking capacity (choices advised by consultee)	Deceased (choices made on behalf of deceased individual)
	Child (parent or guardian choices)	
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	Inappropriate to have discussion
	Patient lacks capacity and no consultee available	Other
Remote consent	Recorded remotely by clinician, no patient signature	
Responsible clinician		
Hospital number		

Healthcare professional name	Signature	Date								
_____	_____	<table border="1"><tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>								

仅供医疗保健专业人员使用

由记录患者选择的医疗保健专业人员填写。

患者类别	成人 (自行做出选择)	临床医生已同意检测 (符合患者的最佳利益)
	无行为能力的成人 (在求询者的建议下做出选择)	已故 (由他人代表已故患者做出选择)
	儿童 (由父母或监护人做出选择)	
检测类型	罕见病和遗传病 - 全基因组测序	癌症 (肿瘤及配对正常组织) - 全基因组测序
如果对研究选项 A 的回答为“否”	患者想之后再讨论	不适合开展讨论
	患者无行为能力, 且没有求询者	其他
远程同意	由临床医生远程记录, 未由患者签名	
负责的临床医生		
医院编号		

医疗保健专业人员姓名	签名	日期								
_____	_____	<table border="1"><tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>								