

Bioethics - Transparency, Privacy, Trust.

Our focus at MimirDNA is to ensure that we can provide you with all the ancestry information you desire, without compromising your privacy and carrying out research that not just the law, but the common man would consider unethical. To that end this statement will make it clear what we at MimirDNA will and will not do with your DNA and how your consent, regardless of what the law tells us we can do, always will come first before anything else. We will explain all methods of the lab in a manner that is clear and concise so that you are never unaware of what is happening with your DNA and always make an informed decision when granting consent.

This document is going to cover the Scientific side of the company and endeavour to describe to you all that can be done, and with your consent will be done with your genomic data.

The key points are:

- Transparency – clearly describe basic lab procedures and what is done with your DNA and data.
- Privacy – how your genomic data is secured.
- Constant improvements upon ethics (through updating methodologies and services).
- Informed consent – always ensuring that you are informed on what we can do, and gain consent for those actions we will undertake.

First, we will cover what your consent can allow us to do in law, take note that we will still ask for consent when it comes to these specific situations, but other companies will not take such a diligent approach.

Regulation for DNA testing comes under the Human Tissue Authority, which is empowered by the Human Tissue Act 2004, you can find a link to the website here ([Who are the HTA? | Human Tissue Authority](#)). Here is a breakdown of what we believe you need to know.

It is an offense to analyse DNA without consent unless it is for an “expected purpose” provided that the analyser of the DNA does not know the identity of the donor. These expected purposes are:

- Clinical audit.
- Determining the cause of death.

- Education or training relating to human health.
- Establishing after a person's death the efficacy of any drug or other treatment administered to him.
- Obtaining scientific or medical information about a living or deceased person which may be relevant to any other person (including a future person).
- Performance assessment.
- Public health monitoring.
- Quality assurance.
- Research in connection with disorders, or the functioning, of the human body.
- Transplantation.

Should you wish us to carry out analysis on your DNA you will of course have to provide consent, however the company will not carry out the above expected purposes without your consent as well. Of the above stated purposes, the only purposes guaranteed to affect you are:

- Clinical audit.
- Education or training relating to human health.
- Obtaining scientific or medical information about a living or deceased person which may be relevant to any other person (including a future person).
- Performance assessment.
- Quality assurance.
- Research in connection with disorders, or the functioning, of the human body.

Clinical audits are efforts to improve standards in the laboratory and ensure all practices are in line with regulations, as a part of the audit methods carried out in the laboratory your DNA may be used to troubleshoot a flawed method, lab workers will never know your identity and so will be unable to carry out tests with your identity in mind. A method of note with regards to this is what is referred to as Gel electrophoresis, it is important to mention this method as it is relevant to the possibility of your identification in the lab. Gel electrophoresis is where DNA is placed into a well of a gel that is then placed into a tank, a current is then run through the gel, causing charged DNA to migrate through the gel and different speeds depending on its size. After a set time the gel is imaged

revealing the positions of the different sized DNA in the gel, this method can be used to validate certain methods in the lab, but the gel created is also unique to you, and how a forensic analyst can identify your DNA at a crime scene. To ensure your privacy any gel image will be deleted following method validation with your DNA, and lab workers will never know the identity of the owner of the DNA they are using.

Education and training relating to human health covers when new lab workers are hired, they will be trained in laboratory methods using spare DNA from tests we have carried out, again your identity is hidden from lab workers so any new hire will not know the owner of the DNA they are using and any data collected will be discarded.

Obtaining scientific or medical information about a living or deceased person which may be relevant to any other person (including a future person). This clause covers the test itself, which will provide us information about your genome, if the test carried out is Microarray genotyping then the information gathered will be the collection of unique single nucleotide polymorphisms (SNP) that are already established and known to be specific to particular ethnic groups (for more information on Micro array genotyping follow this link: [Insert link to info page](#)) with your consent the lab will also carry out next generation sequencing (NGS) if and when it becomes available, this will provide us with your entire genome (whole DNA sequence) which can allow us to find all the unique SNPs in your DNA, not just SNPs that have already been identified by our lab and other labs which have uploaded their findings to international databases (for more information on NGS follow this link: [Insert link to info page](#)).

Performance assessment will be similar to education and training, using your DNA to assess a laboratory worker in our basic practices, in both cases should your DNA be used for this but you have not consented to have your DNA data stored, any data collected will be immediately discarded and as previously stated, no one in the lab will know the identity of the owner of the DNA.

Quality assurance focuses on ensuring that good practice is always undertaken, in the context of our work this will mean testing the viability of your DNA for testing to ensure that it has not degraded thus compromising the validity of tests carried out. Should you choose to not grant consent for use of your DNA in

quality assurance it in theory will not matter as the DNA test should be carried out in a time frame that ensures no degradation has occurred.

Research in connection with disorders, or the functioning, of the human body. This relates to medical and genetic research beyond ethnicity, at this time of the growth of the company we do not intend to carry out such research, however that may change in the future. Should you grant consent for this, and your DNA still be in storage, we may carry out medical research on your DNA, though know that at this time there is no plan to do so.

With your consent the research that is to be carried out on your DNA will be simply the discovery of any new/undiscovered SNPs that are present in your DNA that relate to your particular ethnic group or ancestors. This will be carried out through NGS, should you not want such research conducted then you need to only consent to Microarray genotyping, which will allow us to test your DNA for only the known SNPs related to ethnicity.

As described in our [privacy statements](#), we use multiple layers of physical, technical, and administrative procedures to protect your Data from unauthorized access while conducting our business. These same procedures are used by us to protect your Data used in the Project. In addition, we require our Collaborators and Collaborator Partners to use similar physical, technical, and administrative procedures to protect the Data and Biological Samples we share with them. (this is just copied and pasted from the ancestry website, probably should give a more in-depth assessment on how our data is stored).

An ethical consideration on the part of you is that taking such a DNA test may reveal information about yourself and your ancestry that you were previously unaware of. It may be the case you discover that a direct ancestor such as your father may have lied about their ethnic group to you and your family or that one or both of your parents are in fact not related to you, please be aware of this prior to taking the test.

A further consideration is that it may be the case that despite our best efforts, a hack on our database could result in the exposure of your identity and genetic data to the wider world. There is also a possibility that whilst your DNA is in transit to us that it is stolen.

A key responsibility of all researchers at MimirDNA will be to never fabricate or falsify data, and always act in your best interest, which we believe will be telling you the truth about all results collected in our labs.

Should any of the above change, or any of the rest of the bioethics policy be changed, you will be notified with the standing assumption that you will not desire those changes to impact you. In other words, your consent will be required again should new research be carried out on the DNA donated to us. Below you will find a table of every method that MimirDNA can carry out or may carry out in future and with your permission will carry out to in order to tell you all the information there is in your DNA regarding ancestry and ethnicity, as well as how your DNA and data derived from it may be used.

Method	Do you grant consent yes/no
Do you consent to Micro array genotyping? (basic analysis of your SNPs, that will reveal your ethnic groupings, should you not consent to this then basic analysis of your DNA becomes impossible).	
Do you consent to NGS? (full sequencing of your genome, revealing all your SNPs, those already established by other scientific bodies and those that may be unknown as well, this data will not be shared without consent).	
Do you consent to your DNA being stored after the initial test is done (should you wish another test taken, or our methods update to provide you a better insight into your DNA, we can retest the stored DNA rather than send you a new sample kit)	
Do you consent to the use of your DNA for quality assurance, clinical audits and lab worker training? (all data collected will be deleted, this is purely to train lab workers in our processes and troubleshoot any	

problems that arise in our lab/test that machines are working as intended, this means your DNA will be stored onsite for an extended period of time, between six months to one year).	
Do you consent to medical research? (there is no immediate intention to carry this research, but should the company begin moving in this avenue are you willing to have your DNA used in this context).	
Do you consent to your genome being added to our database to be used as a reference for future work? (consenting to this does not mean your genome will be shared, only that your genome will be used to build up our own database of uniquely discovered SNPs that will contribute to our work).	
Do you consent to having any unique SNPs identified in your genome shared as part of collaborative scientific work? (unless the SNP is unique to you alone, identification of you through this SNP is highly unlikely and only possible if you use other DNA based services).	
Do you consent to having your whole genome shared as a part of collaborative scientific work? (Should you consent to NGS your entire genome will be sequenced, and new SNPs may be discovered in your DNA, whilst your identity will be withheld, your genome is unique to you meaning wider sharing of your genome could lead to your identification should you use other ancestry companies or other DNA based services).	

