**Information on Whole Genome Sequencing for patients**

You have been referred to The London Sarcoma Service for further investigations of a growth in your bone or soft tissues which could be a sarcoma. As part of your care, you may be offered various tests to help best diagnose and plan your treatment. Your doctor will discuss these with you in greater detail. One of these tests is called Whole Genome Sequencing (WGS).

***What is Whole Genome Sequencing (WGS)?***

Your genome is your body’s ‘instruction manual’ and contains nearly all the information needed to create, run and repair you. Your genome is made up of a chemical code called DNA, which is like a series of ‘letters’ that can be looked at using a technique called sequencing. WGS is a genomic test that reads through all the 3.5 billion letters of your DNA that make up your genome. Tumours are caused by cells with abnormal changes in the genome and we can identify some of these changes by comparing your own genome to the genome of the tumour. This could provide helpful information about your diagnosis and may help your healthcare professional to decide the most appropriate treatment option for you.

***What results might you get?***

* **No actionable finding** - this means that the cause of the tumour was not identified in your genome and no actionable results to inform your diagnosis or the most appropriate treatment option were found.
* **Actionable finding** - this means the results could provide information about your diagnosis and the most appropriate treatment option. There may also be a change in your genome that explains why the tumour started. This could indicate whether you have a higher risk of developing other tumour types and whether there may be implications for family members.
* **Uncertain finding** - this means there is a change in your genome that could be the cause of the tumour, but further testing or analysis is needed to help us understand this. For example, we might ask for additional samples or recommend testing of family members. In some cases further testing is not likely to help clarify the finding and we will remain uncertain about whether the change is the cause of your cancer or just part of normal variation. This might become clearer over time and as our knowledge of the genome improves.
* **Incidental finding** - this means there is a change in your genome that is not related to the tumour but could have health implications for you or your family members.

The data from your genomic test will be stored securely within the NHS and will be available for reanalysis in light of new knowledge.

***What will happen if I am offered WGS?***

Your doctor will explain the test, why you are being offered it and how you will get your results. You will be asked to sign a consent form if you agree to the test. If you agree to have the test, you will be asked to provide a blood sample and a section of your tumour tissue will be taken for analysis. As this is a complex test, results are usually available after about 6 months.

***Contributing to research***

Whole genome sequencing is a new and powerful technology that is helping us to further understand tumours and how they develop. In many cases, once we understand the underlying genetic cause we can work with researchers in our universities and industry to develop new treatments.

To help us continue these developments, everyone that has WGS will be offered the opportunity to contribute their anonymised data to the National Genomic Research Library that can be accessed by academic or commercial researchers. Access will be granted and monitored by a committee made up of doctors, clinical academics and patient representatives and no identifiable data will be released. We will also ask your permission for us to contact you should any relevant research studies become available.

Your doctor will discuss this in more detail and ask you to sign a form to say whether you agree to donate your data to research or not. Contributing in this way may help you or your family in the future, and may also help others. If you choose to opt in you are free to change your mind and opt out of the research library at any given point.

If you decide not to have WGS or not to contribute your data for research, you will still receive the best possible care from your doctor. The same applies no matter what the result of your WGS may be, should you choose to have the test.

***For more information about WGS***

Please visit the Genomics England website at

<https://www.genomicsengland.co.uk/understanding-genomics/>

We have also developed a short video to explain genome sequencing in more detail. This explains what a genome is and how genes can cause health problems:

My Genome Sequence:

<http://bit.ly/mygenomesequence>