**Genetic Testing Record of Discussion and Consent Form:**

**Patient Wishes for the Sensitive Disposal/Return of Early-Stage Pregnancy Loss Tissue Following Genomic Testing**

**Referrers:** Please ensure sections 2 and 3 are completed in full. Please send this form to the laboratory together with a fully completed NW GLH referral form and an appropriate patient sample.

**Section 1: Patient Information**

We are very sorry for your loss and understand that this is a difficult time.

You have been advised that genetic laboratory tests using a small sample from your pregnancy may help diagnosis and/or help inform future pregnancies. This form has been prepared to provide you with information about genetic testing to ensure you are aware of our laboratory process and your options.

Genetic testing can look for chromosome changes (missing or extra genetic material). The laboratory requires a very small piece of tissue to be selected and sent to the laboratory to extract DNA. The tests we perform usually take up to about 6 weeks to complete, but some specialist tests can take much longer.

Where possible, we ask to be sent definitively non-fetal tissue (cord, placenta or membrane surrounding the fetus). However, in most early pregnancies it can be difficult to make the distinction between fetal, non-fetal and maternal tissue; this uncertain tissue has the medical term ‘products of conception’. You should be told about what will be sent to the laboratory.

As the sample is very small, DNA extraction usually uses all the sample that we receive for testing and there is no sample left afterwards. However, on occasion, a very small amount of sample remains, and this is stored until after testing is completed.

**Your consent and wishes for sensitive disposal or return of any remaining sample following genetic testing is outlined in Section 2.**

The laboratory will respectfully dispose (by sensitive incineration) any remaining definitively non-fetal cord, placenta, or membrane samples within 12 weeks from the date we received the test request.

We will also respectfully dispose (by sensitive incineration) any remaining products of conception sample without identifiable fetal tissue **unless you choose otherwise, stated in Section 2**. If you wish for other arrangements for the sample (e.g., cremation, burial or your own private arrangements) we will arrange for return to the referral centre.

If the laboratory receives identifiable fetal tissue for testing, any remaining sample will be returned to the referring hospital to fulfil your wishes for respectful and sensitive disposal as stated in section 2.

**Please indicate your consent and wishes on the attached form to avoid any misunderstanding and to enable the genetics laboratory to ensure respectful disposal or return of any remaining sample.**

**Section 2: Patient Consent and Wishes**

**If full information is not provided, the laboratory will sensitively dispose of remaining non-fetal tissue.**

Patient Name: Patient DOB:

NHS Number: Date of referral:

Tissue type to be sent to the laboratory (please tick one option):

□ Umbilical cord (max size 2-3cm) □ Placental tissue (max size 1-2 cm3) □ Products of Conception (POC) tissue

|  |
| --- |
| **To be completed by the patient or by the referrer under the direction of the patient:**  |
| 1. If there is any remaining tissue that is identifiable as **fetal** this will be returned to the referring centre (return address must be stated in section 3)

I wish the referring centre to arrange for: (please choose 1 option only)□ cremation □ burial (if available)□ return to me for private arrangements □ unable to decide now |
| 1. If there are any remaining **products of conception (POC)** **of uncertain tissue** left after DNA extraction

I wish the genomic laboratory to: (please choose 1 option only)□ arrange sensitive disposal □ return remaining tissue to the referring centre *(please complete question 3\* and return address must be stated in section 3)*□ unable to decide now but agree to inform the referrer within 12 weeks if I do not wish the sample to be sent for sensitive disposal |
| 3. \*If return of tissue was selected in question 2, I wish to make arrangements for POC of uncertain tissue with the referrer for: (please choose 1 option only)□ cremation □ burial (if available) □ return to me for private arrangements |

|  |
| --- |
| **To be completed by the referrer:** |
| I confirm that the patient has been given and understood the information in Section 1 and 2 and that any questions asked have been answered to their satisfaction and understanding. I confirm that the woman’s wishes have been accurately determined and consent given for genetic testing.**I have provided details for return of any tissue samples to my referring centre (section 3).** |
| Referrer full name and job title: |  |
| Date: |  |
| Signature: |  |

**Section 3: RETURN OF SAMPLE**

**\*Please provide contact name, role and full postal address to enable safe return of any tissue in accordance with patient choices.** **If this information is not provided, the laboratory will arrange sensitive disposal of any tissue not identified as fetal for which return has been requested.**