

ETHICS CHECKLIST

If you wish to contribute monogenic cases / families to GP2, you will be asked first to answer the following questions.

Please note that if you choose any of the red answers, your consent will not be eligible for data sharing within the GP2. Please check our [“Consent Guidelines and Recommendations”](#) for guidance on how to draft a new consent form and contact Monogenic Team for support.

Institutional Review/Ethics Review Board

Which ethics committee reviewed and approved this human subject research?

Date of ethics board approval

Data Sharing

What are the terms of data sharing outlined in the consent documents?

- Use limited to study for which they were originally collected
- Use limited to PI/Institution at which the study was conducted
- Use limited to Parkinson's disease research
- Consent silent on future use
- Consent explicitly allows sharing of data
- Consent explicitly allows international sharing of data
- Other

Sample Sharing

What are the terms of sample sharing outlined in the consent documents?

- Use limited to study for which they were originally collected
- Use limited to PI/Institution at which the study was conducted
- Use limited to Parkinson's disease research
- Consent silent on future use
- Consent explicitly allows sharing of samples
- Consent explicitly allows international sharing of samples
- Other

Duration of Storage

Is the duration of data storage limited?

- Limited
- Consent silent on duration of storage
- Unlimited
- Other

If storage duration is limited, when does it expire?