

## ***Gaining Consent to share data: information for practitioners***

We have agreed an “opt in” approach to data sharing. This means asking children, young people or their parents/guardians as relevant, for permission to share their data;. This permission covers: answers to questionnaires and some key personal details such as name and address, so that different pieces of information can be linked to allow meaningful analysis (e.g. a child’s questionnaire responses can be linked to the number of sessions they were seen for and the sort of treatment they received).

Before we analyse the data we will delete all personal details and only use the anonymised data for analysis and reporting

### ***The approach we are taking***

We have been advised to follow the process used for gaining consent for use of patient reported outcome measures in elective surgery. This involves asking the first time a questionnaire is completed for permission to use the data from this and subsequent questionnaires.

### ***Who gives consent?***

If a young person is over the age of 16 they can give independent consent without parental input unless there are exceptional circumstances (such as where they are deemed unable to make independent decisions for some reason)

If a young person is under the age of 16 but judged “Gillick competent”, i.e. able to understand and retain the information about the decision they are making and can weigh up and use this information in coming to their decision, then they too can legally give consent without parent or guardian authorisation.

If a young person is under the age of 16 and **not** judged Gillick competent, i.e. not able to understand and retain the information about the decision they are making and cannot weigh up and use this information in coming to their decision, then parent or guardian authorisation is required.

### ***Who completes the form?***

There are two consent forms: one for young people and one for their parents/guardians. Only **ONE** needs to be completed. Please ask for the **ONE** to be completed that you deem relevant

If the young person is judged “Gillick competent” and completes the young person form, but they and you would like the parent to sign the form also that is fine –just ask the parent/guardian to add their signature to the bottom of the form for young people.

If the parent is the one giving authorisation but you and they feel it makes sense for the “non-Gillick” competent child to sign that is also fine – they can add their signature on the form for parents.

### ***Participation is voluntary***

If authorisation is not given or withdrawn at any time please ensure this is recorded on your relevant database so that the information in question can be excluded from data sharing.

## ***Child or Young Person's Consent to share information:***

### ***Consent to share information:***

During treatment, you may be asked to complete questionnaires about how you feel, how much progress you are making towards achieving treatment goals, and how helpful you think the service has been. Your therapist will regularly check these with you to make sure they are helping the best they can.

### ***Our request***

We are asking your permission to use answers to these questionnaires along with information about the care you receive to collect information about the quality of the services across the country provided for children, young people and their families.

### ***Our promise***

Nationally, we will report only group information, for instance how many people with particular problems have recovered by the end of treatment and how effective different kinds of treatments seem to be.

It will not be possible to identify you personally, because we will make the information anonymous, this means we will remove any personal information that could identify you like your name, address or date of birth.

Once we have made the information anonymous, we will only look at and write reports on information from groups of people, not individuals. For example, this could be how many people with a particular problems have got better by the end of treatment or it could look at how effective different types of treatments are."

### ***By signing this consent form you are agreeing that:***

Your personal details and questionnaire responses will be held securely by MegaNexus, who are providing secure data storage to support national analysis. All the information will be handled securely so only a limited number of authorized people can see it.

Any identifying information, such as your name, address, date of birth, and NHS ID, will be removed and will not be seen by people analysing the information. This anonymised information will be analysed by the CAMHS Outcomes Research Consortium (CORC) and the Evidence Based Practice Unit at University College London and the Anna Freud Centre, and may be used by other research groups to help make services as good as they can be.

No one involved in the handling or analysis of information will release your personal information unless required by law or where there is a clear overriding public interest.

### ***Your participation is voluntary***

You may withdraw your consent for this information to be shared up to the point at which data are analysed and personal details removed. Please talk to the person working with you if you have any concerns or queries

I agree for my personal details and questionnaire responses to be held securely, on the understanding that all identifying information will be removed before analysis and before any publication.

**YES**

**or**

**NO**

**(please circle)**

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date \_\_\_\_\_

## Parental Consent to share information:

During treatment, you and your child may be asked to complete questionnaires about how you and your child feel, how much progress is being made towards achieving treatment goals, and how helpful you think the service has been. The therapist will regularly check these with you to make sure they are helping the best they can.

### Our request

We are asking your permission to use answers to these questionnaires along with information about the care your child receives. This is to collect information about the quality of the services provided for children, young people and their families.

### Our promise

Nationally, we will report only group information, for instance how many people with particular problems have recovered by the end of treatment and how effective different kinds of treatments seem to be.

It will not be possible to identify your child personally, because we will make the information anonymous. This means any personal information that could identify your child like their name, address or date of birth will be removed before the data are passed on for analysis. It will also not be possible to identify you, as their parent or carer.

Once we have made the information anonymous, we will only look at and write reports on information from groups of people, not individuals. For example, this could be how many people with a particular problems have got better by the end of treatment or it could look at how effective different types of treatments are."

### By signing this consent form you are agreeing that:

Your child's personal details and questionnaire responses will be held securely by MegaNexus, who are providing secure data storage to support national analysis. All the information will be handled securely so only a limited number of authorized people can see it.

Any identifying information, such as your child's name, address, date of birth, and NHS ID, will be removed and will not be seen by people analysing the information. This anonymised information will be analysed by the CAMHS Outcomes Research Consortium (CORC) and the Evidence Based Practice Unit at University College London and the Anna Freud Centre, and may be used by other research groups to help make services as good as they can be.

No one involved in the handling of information will release your child's personal information unless required by law or where there is a clear overriding public interest.

### Your participation is voluntary

You may withdraw your consent for your child's personally identifiable information to be held. Please talk to the person working with you and your child if you have any concerns or queries.

I agree for my child's personal details and questionnaire responses to be held securely, on the understanding that all identifying information will be removed before analysis and before any publication.

YES

or

NO

(please circle)

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date \_\_\_\_\_