



FamilySleeps



FamilySleeps: Investigation of circadian rhythms and sleep in families: a focus on autism

Sample Consent Form for Adult Participants

It must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.

If you agree to your participation in this research study, please complete the consent form below.

	Yes	No
I have read (or been read to) the information about the FamilySleeps study. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction.		
I understand the information provided in the FamilySleeps information leaflets and what taking part in this study involves.		
I confirm that I have read the inclusion and exclusion criteria and that my family is eligible to participate.		
I am willing to participate in the FamilySleeps project, and I feel under no obligation to do so.		
I understand that the information collected in the study will be kept strictly confidential.		
I understand that I can withdraw myself and my data from the study at any point without giving an explanation.		
I understand that I cannot withdraw my data from the study after the results of the study have been published.		
I freely and voluntarily agree to be a part of this research study, having been made fully aware of the risks and benefits.		



FamilySleeps



Maynooth University
National University
of Ireland Maynooth

Consent to the Use of Personal, Questionnaire, Sensor and Genetic Data	Yes	No
I consent to the use of the information collected about me (personal data, questionnaire data, sensor data and genetic data) for this study, as outlined in the Information Leaflets.		
I consent to my saliva sample and biological sex information to go to a third-party service provider (TBD) for DNA extraction. I know that they will not retain these saliva samples or biological information.		
I consent to my questionnaire data being shared with a third-party service provider onlinesurveys.ac.uk. I know that all survey data will be retained and hosted on a third-party (Online Surveys) server and not on a Maynooth University server.		
I consent to my name being shared with onlinesurveys.ac.uk in relation to my consent form. I know that all survey data will be retained and hosted on a third party (Online Surveys) server and not on a Maynooth University server.		
I consent to my DNA sample and my biological sex information being sent to a third-party service provider for genetic analysis (where they will analyse my genetic code). I know that they will not share this data with anyone outside of the research team at Maynooth University and that they will not retain this data. I know that this data will be stored for 10 years after completion of the study in pseudonymised form in Maynooth University.		

Data Retention, Data Sharing and Future Research	Yes	No
I consent to my pseudonymised questionnaire data, sensor data and genetic data being retained for 10 years after completion of this study. I know that this pseudonymised data could be used in future research.		
I consent to being recontacted by a member of the research team 10 years after completion of the study to ask for consent to continue to retain my data for future research.		

Participant's Name (Printed):.....

Participant's Signature:.....

Date:.....



Researcher's Note:

Name of Researcher:.....

Signature:.....

Date:.....

Consent collected	In person	<input type="checkbox"/>
	Over phone	<input type="checkbox"/>
	By Email	<input type="checkbox"/>



FamilySleeps



Sample Consent Form for Parents of an Autistic Child

It must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.

If you agree to your child's participation in this research study, please complete the consent form below.

	Yes	No
I have read (or been read to) the information about the FamilySleeps study. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction.		
I understand the information provided in the FamilySleeps information leaflets and what taking part in this study involves.		
I confirm that I have read the inclusion and exclusion criteria and that my family is eligible to participate.		
I am willing for my child to participate in the project, and I feel under no obligation to allow this participation.		
I understand that the information collected in the study will be kept strictly confidential.		
I understand that I can withdraw my child's participation and data from the study at any point without giving an explanation.		
I understand that I cannot withdraw my child's data from the study after the results of the study have been published.		
I freely and voluntarily agree for my child to be a part of this research study, having been made fully aware of the risks and benefits.		
I consent to share my child's clinical diagnosis of autism (in the form of a clinical report from my child's clinicians) with the researchers.		



Consent to the Use of Personal, Clinical, Questionnaire, Sensor and Genetic Data	Yes	No
I consent to the use of the information collected about my child (personal data, clinical (medical) data, questionnaire data, sensor data, and genetic data) for this study.		
<p>I consent to the following data about my child being shared with a third-party service provider (VitalThings):</p> <p>(i) Sensor data</p> <p>(ii) Age</p> <p>(iii) Biological sex</p> <p>I understand that sharing these data is essential for the purpose of analysing this data.</p> <p>I know that this data will be stored for 10 years after completion of this study in pseudonymised form in Maynooth University.</p>		
I consent to my child's saliva sample and biological sex information to go to a third-party service provider (TBD) for DNA extraction. I know that they will not retain these saliva samples or biological information.		
I consent to my child's questionnaire data being shared with a third-party service provider onlinesurveys.ac.uk. I know that all survey data will be retained and hosted on a third-party (Online Surveys) server and not on a Maynooth University server.		
I consent to my child's name being shared with onlinesurveys.ac.uk in relation to my child's assent form. I know that all survey data will be retained and hosted on a third-party (Online Surveys) server and not on a Maynooth University server.		
I consent to my child's DNA sample and biological sex information being sent to a third-party service provider for genetic analysis (where they will analyse my child's genetic code). I know that they will not share this data with anyone outside of the research team at Maynooth University and that they will not retain this data. I know that this data will be stored for 10 years after completion of the study in pseudonymised form in Maynooth University.		



FamilySleeps



Maynooth University
National University
of Ireland Maynooth

Data Retention, Data Sharing and Future Research (My Child's Data)	Yes	No
I consent to my child's pseudonymised questionnaire data, sensor data and genetic data being retained for 10 years after completion of the study.		
I know that this pseudonymised data could be used in future research..		
I consent to being recontacted by a member of the research team 10 years after completion of the study to ask for consent to continue to retain my and my child's data for future research.		

Parent's Name (Printed):.....

Parent's Signature:.....

Date:.....

To be Completed by the Researcher	Yes	No
I have fully explained the purposes and nature of this research to the participant in a way that s/he can comprehend, and I have invited him/her to ask questions about the study.		
I have explained the potential for risks and benefits to the participant in a way that s/he can comprehend.		
I confirm that I have provided the participant with copies of the information leaflets and consent forms.		

Researcher's Note:



FamilySleeps



Maynooth University
National University
of Ireland Maynooth

Name of Researcher:.....

Signature:.....

Date:.....

Consent collected

In person
Over phone
By Email

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>



FamilySleeps



Maynooth University
National University
of Ireland Maynooth

Sample Consent Form for Parents of a Non-Autistic Child (Families with an Autistic Child)

It must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.

If you agree to your child's participation in this research study, please complete the consent form below.

	Yes	No
I have read (or been read to) the information about the study. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction.		
I understand the information and what taking part in this study involves.		
I confirm that I have read the inclusion and exclusion criteria and that my family is eligible to participate.		
I am willing for my child to participate in the project, and I feel under no obligation to allow this participation.		
I understand that the information collected in the study will be kept strictly confidential.		
I understand that I can withdraw my child from the study at any point without giving an explanation.		
I understand that I cannot withdraw my child's data from the study after the results of the study have been published.		
I freely and voluntarily agree for my child to be a part of this research study, having been made fully aware of the risks and benefits.		



Consent to the use of Personal, Questionnaire, Sensor and Genetic Data	Yes	No
I consent to the use of the information collected about my child (personal data, questionnaire data, sensor data, and genetic data) for this study, as outlined in the information leaflet.		
I consent to my child's saliva sample and biological sex information to go to a third-party service provider (TBD) for DNA extraction. I know that they will not retain these saliva samples or biological information.		
I consent to my child's questionnaire data being shared with a third-party service provider onlinesurveys.ac.uk. I know that all survey data will be retained and hosted on a third-party (Online Surveys) server and not on a Maynooth University server.		
I consent to my child's name being shared with onlinesurveys.ac.uk in relation to my child's assent form. I know that all survey data will be retained and hosted on a third-party (Online Surveys) server and not on a Maynooth University server.		
I consent to my child's DNA sample and biological sex information being sent to a third-party service provider for genetic analysis (where they will analyse your and your child's genetic code). I know that they will not share these data with anyone outside of the research team at Maynooth University and that they will not retain these data. I know that these data will be stored for 10 years after completion of the study in pseudonymised form in Maynooth University.		

Data Retention, Data Sharing and Future Research (My Child's Data)	Yes	No
I consent to my child's pseudonymised questionnaire data, sensor data and genetic data being retained for 10 years after completion of this study. I know that this pseudonymised data could be used in future research.		
I consent to being recontacted by a member of the research team 10 years after completion of the study to ask for consent to continue to retain my and my child's data for future research.		



FamilySleeps



Maynooth University
National University
of Ireland Maynooth

Parent's Name (Printed):.....

Parent's Signature:.....

Date:.....

To be Completed by the Researcher	Yes	No
I have fully explained the purposes and nature of this research to the participant in a way that s/he can comprehend, and I have invited him/her to ask questions about the study.		
I have explained the potential for risks and benefits to the participant in a way that s/he can comprehend.		
I confirm that I have provided the participant with copies of the information leaflets and consent forms.		

Researcher's Note:

Name of Researcher:.....

Signature:.....

Date:.....

Consent collected

In person

☐

Over phone







☐




By Email

☐

Sample Assent Form for Children with Autism

If you agree to take part in this research study, please read, tick and sign below.

	<p>I have read the information about this study, or one of the researchers has read it to me. I understand it all.</p>	
	<p>I have had the opportunity to ask questions and all my questions have been answered by the researchers.</p>	
	<p>I am willing to take part in the project and I know that I do not have to take part.</p>	
	<p>I agree to wear a watch for two weeks at four different timepoints to measure my movement and sleep patterns.</p>	
	<p>I agree that my parents can fit sensors that measure movement in my bedroom and my sleep for 12 months.</p>	
	<p>I agree to spit into a tube and give the tube to the researchers.</p>	

	I know that the researchers will use some of my spit to look at my DNA which carries all the information about how my body works. DNA is found in every cell in our bodies and makes up who we are.	
	I agree to allow the researchers at Maynooth University to use some personal information about me, like my name and age, for this study.	
	I know that I don't have to take part in this study and that I can stop taking part at any time. I can tell my parents, or the researchers and I will be taken out of the study.	

Child's Name (printed):.....

Child's Signature:.....

If your child cannot sign their name for any reason, they can tick/mark the following box to indicate they assent to taking part in this study:

☐

Parent's Name (printed):.....

Parent's Signature:.....

Date:.....



FamilySleeps



Maynooth University
National University
of Ireland Maynooth

To Be completed by the Researcher:	Yes	No
I have fully explained the purposes and nature of this research to the participant in a way that s/he can comprehend, and I have invited him/her to ask questions about the study.		
I have explained the potential for risks and benefits to the participant in a way that s/he can comprehend.		
I confirm that I have provided the participant and his/her parent/guardian with copies of the information leaflets and consent forms.		

Researcher's Note:

Name of Researcher:.....

Signature:.....

Date:.....

Consent collected

In person







Over phone

By Email

☐☐☐

Sample Assent Form for Children without Autism (Families with an Autistic Child)

If you agree to take part in this research study, please read, tick and sign below.

	<p>I have read the information about this study, or one of the researchers has read it to me. I understand it all.</p>	
	<p>I have had the opportunity to ask questions and all my questions have been answered by the researchers.</p>	
	<p>I am willing to take part in the project and I know that I do not have to take part.</p>	
	<p>I agree to wear a watch for two weeks at four different timepoints to measure my movement and sleep patterns.</p>	
	<p>I agree to spit into a tube and give the tube to the researchers.</p>	
	<p>I know that the researchers will use some of my spit to look at my DNA which carries all the information about how my body works. DNA is found in every cell in our bodies and makes up who we are.</p>	



FamilySleeps



Maynooth University
National University
of Ireland Maynooth

	I agree to allow the researchers at Maynooth University to use some personal information about me, like my name and age, for this study.	
	I know that I don't have to take part in this study and that I can stop taking part at any time. I can tell my parents, or the researchers and I will be taken out of the study.	

Child's Name (printed):.....

Child's Signature:.....

If your child cannot sign their name for any reason, they can tick/mark the following box to indicate they assent to taking part in this study:

☐

Parent's Name (printed):.....

Parent's Signature:.....

Date:.....



FamilySleeps



Maynooth University
National University
of Ireland Maynooth

To Be completed by the Researcher:	Yes	No
I have fully explained the purposes and nature of this research to the participant in a way that s/he can comprehend, and I have invited him/her to ask questions about the study.		
I have explained the potential for risks and benefits to the participant in a way that s/he can comprehend.		
I confirm that I have provided the participant and his/her parent/guardian with copies of the information leaflets and consent forms.		

Researcher's Note:

Name of Researcher:.....

Signature:.....

Date:.....

Consent collected

In person

☐

Over phone

☐

By Email

☐