

## 受访知情同意书

尊敬的\_\_\_\_\_:

您好!

您被邀请参加一项关于“影响自闭症儿童家庭寻求医疗支持的心理社会因素”的研究，本知情书提供给您一些信息，在您决定是否参加该项目之前，请尽可能仔细阅读下文内容。它可以帮助您更好地理解项目的目的、程序。请您仔细阅读，如果有任何问题可以向研究人员提出，研究人员会及时为您解释，直到您完全理解。

**1、项目课题：**影响自闭症儿童家庭寻求医疗支持的心理社会因素

**2、研究调查者：**鞠思瀚、张祎泠、赵林峰、王艳、季逸圣

**3、项目研究目的：**了解对于疑似自闭症患儿家庭，影响其产生寻求医疗支持（包括诊断与治疗）动机的心理、社会因素。

### **4、研究过程**

采访对象：自闭症患儿监护人

采访内容包含：

家庭关于自闭症的知识背景；

家庭寻求医疗支持的基本信息（如时间等）；

家庭在寻求医疗支持过程中的心理状态（如决策过程等）；

家庭在寻求医疗支持过程中的社会因素（如社会医疗制度、个人社会支持网络、文化环境及经济因素）。

采访方式：面对面访谈

采访时长：共 10 个核心问题，约 30 分钟

### **5、参加本研究可能出现的不便与风险**

参加该研究不便在于：会占用您大约 30 分钟的工作或生活时间，受方人员将尽力根据您的时间安排采访，尽量减少对您造成的不便。

参加该研究的风险在于：部分问题可能涉及个人隐私。具体对于隐私的保护您可以参见下文的隐私保密条款，并且在采访中，您有权拒绝回答任何您觉得涉及隐私的问题。

### **6、个人信息及记录的保密**

如果您决定参与本次研究，您参与本次研究以及您在研究中的个人资料将严格保密。所有研究组人员将对您的个人信息进行严格保密，可识别您身份的信息

将不会透露给研究组外成员，除非获得您的许可。您的资料将会被保存在设置密码的文件硬盘内，仅供研究人员查阅。

## **7、关于中途退出研究**

在接受采访过程中，如果您有疑惑可以随时提出问题。如果该研究引起您极度不适，或因您的个人原因，您无法继续参与本次研究，请尽快告知研究人员，以便我们与您沟通以及项目的后续安排。

## **8、联系人**

如果您对于研究或是将来在研究中有任何问题，或者您认为您在研究中收到了研究人员的不公正对待，请及时联系我们：

联系负责人：刘星吟

邮箱：xingyinliu@njmu.edu.cn

电话：86869397

我自愿参与本次研究活动，对以上所有信息我已经知情，对于相关问题我已经和研究人员联络并得到答复，并已了解我的个人信息是保密且受保护的，在研究过程中我可以随时退出该项目。

签字：

日期：

## Consent form

Dear \_\_\_\_\_:

You are invited to participate in a study on “Psychosocial Factors Affecting Families of Autistic Children to Seek Medical Support”. This consent form provides you with some information. Please read the following content as carefully as possible before deciding whether to participate in the project. It can give you a better understanding of the purpose and procedures of the study. Please read it carefully. And if you have any questions, please let researchers know and they will explain to you in time.

1. **Project Topics:** Psychosocial Factors Affecting Families of Autistic Children to Seek Medical Support
2. **Research Investigators:** Sihan Ju、Yilin Zhang、Linfeng Zhao、Yan Wang、Yisheng Ji
3. **Research Purpose:** To understand the psychological and social factors that influence the motivation of suspected autistic children’s families to seek medical support(including diagnosis and treatment).

**4. Research process:**

Interviewees: Guardian of children with autism.

The interview content :

- (1) Family’s knowledge of autism.
- (2) Basic information for families seeking medical support(such as time, etc.).
- (3) The psychological state of the family when seeking medical support(such as the decision-making process, etc.).
- (4) Social factors when families seeking medical support(such as social medical system, personal social support network, cultural environment, economic factors, etc.).

Interview Method: Face to face interview

Interview duration: 10 core questions, about 30 minutes

**5. Possible inconveniences and risks of participating in this study:**

The inconvenience of participating in the study is that it will take you about 30 minutes of your working or living time. We will arrange the interview according to your schedule to minimize the inconvenience caused to you.

The risk of participating in the study is that some questions may involve your privacy. For the specific protection of privacy, you can refer to the privacy and confidentiality items below. During the interview, you have the right to refuse to answer any questions that involve your privacy.

**6. Confidentiality of personal information and records:**

If you decide to participate in this study, your participation and personal information in the study will be kept strictly confidential. All research investigators will keep your information confidential. Information that can identify you will not be disclosed to members outside the research team unless your permission is granted. Your data will be stored in the hard disk with a password for researchers’ access only.

**7. Withdrawal of the research:**

During the interview, please feel free to ask any questions if you are in doubt. If the study causes you extreme discomfort, or for your reasons, you are unable to continue to participate in this

study, please inform the researchers as soon as possible so that we can communicate with you and the follow-up arrangement of the project.

8. **Contact:**

If you have any questions about research or future research, or if you think you have been unfairly treated by the researchers in the research, please contact in time.

Contact person in charge: Xingyin Liu

Email: [xingyinliu@njmu.edu.cn](mailto:xingyinliu@njmu.edu.cn)

Phone number:86869697

I volunteered to participate in this research. I have been informed of all the above information, I have contacted the researcher and received an answer to the question. I understand that my personal information is confidential and protected. I can withdraw from the project at any time during the study.

The signature:

Date: