CONSENT FORM
知情同意书

AphasiaBank: A Database for the Study of Language and Communication in Aphasia
AphasiaBank: 为了研究失语症患者的语言与交流方面而建立的数据库系统

INTRODUCTION
研究项目介绍

As a native speaker of Mandarin, you are being invited to participate in a research study testing the validity of the Mandarin version of the AphasiaBank protocol which will be used to collect data from people with aphasia who are native speakers of Mandarin. The purpose of the study is to construct a shared database of multimedia interactions for the study of communication in those with aphasia. The study will involve you describing pictures, discussing events in your life, telling a traditional story, describing the procedure of making a traditional food, repeating words and sentences, and naming pictures of actions and objects.
作为一个以中文为母语的人，您被我们邀请参与一个测试 AphasiaBank 试验计划书的效度的研究，本试验计划书将用于对于以中文为母语的失语症病患的数据采集。本研究项目的目的是建立一个有关研究失语症患者沟通方面的多媒体分享数据库项目。 在这个研究当中，您将参与描述图片，讲述生活经历，讲一个传统的故事，描述制作一个传统食品的过程，复述单词和句子，和根据图片说出动作和物体的名字。

This research study will be conducted at the University of Kansas Medical Center with Susan Jackson, Ph.D., L/CCC-SLP as the principal investigator. Approximately 5 subjects per year will be enrolled at KUMC.
本研究项目将在堪萨斯大学医学研究中心由首席研究员 Susan Jackson 博士负责执行。每年招收大约五名研究对象。

You do not have to participate in this research study. Before you make a decision to participate, you should read the rest of this form. The main purpose of research is to benefit future patients and society in general. You might get personal benefit from participating in this study, but you should understand that the purpose of research is to create new knowledge.
对于本研究项目的参与不是强制性的。在您决定参与与否之前，请阅读这份文件的以下部分。这个研究项目的主旨在于造福未来的病患和社会大众。您可能会因参与此项研究而受益，但同时您应当了解本研究项目的目的在于实现学术突破。

BACKGROUND
背景资料

This study is funded by the National Institutes of Health (NIH) to develop new treatments for language disorders. Aphasic symptoms vary greatly from person to person. It is likely that some treatments will be more effective for some people with aphasia and less effective for others. This means that determining treatment effects will require a large number of measures

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collected from a large population of patients receiving various treatments.
国立卫生研究院为本失语症研究提供经费赞助，旨在发展新的语言障碍治疗方案。每个病患的失语症症状各不相同。一些治疗方案可能对某些病患更有效，对于其他病患并不能达到同样疗效。这就意味着我们需要大量的接受不同治疗方案的病患提供数据来测定各种治疗方案的疗效。

Currently, determining treatment effects in aphasia relies primarily on standardized tests of language ability. However, the goals of therapy relate to the quality of language use in context, not on standardized measures. Thus, it is crucial that research studies of treatment effects also include measures gathered directly from actual language use in real communication situations. Data on language processing in aphasia is important for the advance of research on patient-oriented treatments. It is important for the advance of theories in many areas of study. Data on language use in aphasia plays an important role in advancing theories in linguistics, psychology, neuroscience, education, and sociology.
现今决定失语症治疗效果主要依赖于对于语言能力的标准化测试结果。然而，理疗的目标是基于提高一定背景下的语言应用能力，并非标准化测试结果。因此，收集病患在实际生活中的沟通能力情况是对于疗效研究的关键。有关失语症患者语言处理能力的数据对于促进以患者为中心的治疗方案研究是非常重要的。这些数据对于促进本领域相关原理的发展也是非常重要的。有关失语症患者语言使用情况的数据对于语言学，心理学，神经科学，教育学以及社会学相关原理的进步有重要作用。

Until recently, the technology supporting video- and audio-based databases was too weak to allow serious consideration of an international database on communication in aphasia. However, recent advances in computer technology have now made it possible for researchers to link high quality digital (electronic) recordings to written transcriptions of the speaker's spoken words.
直到近些年来，支持以语音和视频为基础的数据库技术依旧薄弱，不足以应用到支持建立国际化的失语症沟通数据库。然而，近些年来计算机技术的进步使得研究人员可以在阅读书写记录的同时观看病患的测试录像。

The construction of AphasiaBank will have a revolutionary impact on the study of aphasia. Students of aphasic communication have had no access to a shared database or to state-of-the-art tools needed to do their basic research. As a result, this field has not received benefit from the computer technology developments that have revolutionized other areas in medicine and the social sciences. Once these barriers are removed, it will lead to rapid improvements in the science-based study of language in aphasia.
AphasiaBank 的建立对于失语症的研究有着革命性的意义。研究失语症沟通的学生从未有机会接触到共享数据库，或者使用必要的现有技术做基本的研究。因此，这个领域并没有受益于计算机技术的发展，尽管这项技术的发展已经给其他领域诸如医药学以及社会科学带来了革命性的进步。一旦攻破了技术障碍，科学的失语症语言研究将会有快速的发展。

PURPOSE
研究目标

The purpose of this study is to test the validity of the Mandarin version of the ApahsiaBank protocol so that it can be used to gather data for the study of language and communication in people with aphasia.

本研究项目的目的在于测试中文版 AphasiaBank 试验计划书的效度，用来为失语症患者语言及沟通研究的网络数据库采集数据。

PROCEDURES
步骤

If you are eligible and decide to participate in this study, you will participate in one session lasting approximately one hour. This session will be videotape recorded. You will be asked to describe pictures, tell a story about your personal experience, and tell the Cry Wolf story or the Tortoise and the Hare story. You will be asked to describe how to make dumplings. You will also be asked to repeat single words and sentences and name pictured actions and objects.

如果您符合招入标准，并且同意参与此研究项目，您将会参与一个大约持续一个小时的活动。届时我们将对此活动录像。在此活动中，您将被要求描述图片，讲述您的经历，然后再讲“狼来了”或者“龟兔赛跑”的故事，描述如何制作饺子。您还将被要求复述单词和句子，根据图片说出动作和物体的名字。

The data collected during the assessment will be used to test the validity of the Chinese translation of the AphasiaBank protocol. Participants in this study will be videotape recorded. The videotapes may be shared with researchers who study language disorders on the Internet. The video will show your face, so it will be possible to identify you from the video on the Internet. Members of the AphasiaBank group will be the individuals viewing the videotapes. They will not be allowed to share the information from the tapes with others.

测试获得的数据将被用来测试中文版的 AphasiaBank 试验计划书的效度。参与者将会被录像。这些录像将会被放在网络上供失语症语言障碍的研究人员分析研究。您的脸部会呈现在录像中，所以观看网上录像者有可能认出您。观看录像的人员皆为 AphasiaBank 的成员。与外界分享录像中的信息是被禁止的。

RISKS
风险

There are no known risks or discomforts associated with this study. You may get tired, but you may take a break at any time. Since your face will be shown in the video, it is possible that you will lose confidentiality of your health information.

本研究项目没有任何已知风险和不适。您可能会中途感到疲劳，但是您可以在任何时间停下休息。鉴于录像中会呈现您的脸部，您有可能丧失健康信息的机密性。

NEW FINDINGS STATEMENT
新发现声明

You will be informed if any significant new findings develop during the course of the study that may affect your willingness to participate in this study.

我们将会及时通知您有可能影响到您参与决定的本研究的新发现。

BENEFITS
收益

You will not benefit from participating in this study.

参与此研究项目不会给您带来收益。

ALTERNATIVES
可选择性

Participation in this study is voluntary. Deciding not to participate will have no effect on the care or services you receive at the University of Kansas Medical Center.

对于本研究项目的参与是自愿的。拒绝参与此研究项目不会影响到您在堪萨斯大学医学中心接受的治疗服务。

COSTS
花费

There are no costs to you related to participation.

参加此项目不需要任何花费。

PAYMENT TO SUBJECTS
研究对象薪酬

You will not receive payment for participating in this study.

参与此研究项目不包含任何酬劳。

IN THE EVENT OF INJURY
受伤情况

No participants are expected to have any injury or illness due to this research study. You do not give up any of your rights by signing this form. If you are hurt by the study or have any other type of problem during the study, you should immediately contact Susan Jackson at 913-588-5937.

任何参与者都不会因此研究受伤或患病。签知情同意书并不代表您放弃了任何权利。假如您在参与当中受伤或发生其他问题，请立即拨打电话 913-588-593 联系 Susan Jackson。

INSTITUTIONAL DISCLAIMER STATEMENT
学院免责声明

If you believe you have been injured as a result of participating in research at Kansas University Medical Center (KUMC), you should contact the Director, Human Research Protection Program, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160. Compensation to persons who are injured as a result of participating in research at KUMC may be available, under certain conditions, as determined by state law or the Kansas Tort Claims Act.

如果您确信您因为参与在堪萨斯大学医学中心的研究项目而受伤，请联系参与研究人员保护项目的主管，地址为 Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160。 由于参与在 KUMC 的研究项目受伤，由堪萨斯州周法律或者 the Kansas Tort Claims Act 决定是否进行赔偿。

CONFIDENTIALITY AND PRIVACY AUTHORIZATION
机密性和隐私授权

Study records that identify research participants will be kept confidential as required by law. Researchers cannot guarantee absolute confidentiality. Efforts will be made to keep your personal information confidential. If the results of this study are published or presented in public, information that identifies participants will be removed.

能够辨认出研究对象的研究记录将会按照法律要求保密。研究人员不能保证绝对的保密。我们将尽力保证您的个人信息安全。在公开研究成果的时候，能够辨认出参与者的信息将会被移除。

The privacy of health information is protected by a federal law known as the Health Insurance Portability and Accountability Act (HIPAA). By signing this consent form, you are giving permission ("authorization") for KUMC to use and share health information about you for purposes of this research study. If you decide not to sign the form, you cannot be in the study.

个人健康隐私被叫做 Health Insurance Portability and Accountability Act (HIPAA)的联邦法律所保护。签了这份知情同意书之后，您将授权我们使用和分享您的健康信息用于此研究项目。假如您决定不签署这份知情同意书，您将不能参与到此项研究中。

To do this research, the research team needs to collect health information that identifies participants. The information may include items such as name, address, phone number, date of birth, social security number, or other identifiers. The research team will collect information from study activities described in the Procedures section of this form and information from the medical record that relates to study participation. The health information will be used at KUMC by Dr. Susan Jackson, members of the research team, The University

of Kansas Hospital Medical Record Department, the KUMC Research Institute and officials at KUMC who oversee research, including members of the KUMC Human Subjects Committee and other committees and offices that review and monitor research studies.
为了进行此研究，研究团队需要收集您的健康信息来对参与者加以区分。我们收集的信息包括您的姓名，住址，电话号码，出生年月，社会安全号，或其他信息。本研究团队将收集从研究步骤中获得的有关您的信息和有关参与此研究项目的医疗记录。使用您的健康信息的包括堪萨斯大学医学中心的 Susan Jackson 博士以及此研究团队，还有堪萨斯大学医院医疗记录科，堪萨斯大学医学中心研究院，以及监督此研究项目的官员们，包括堪萨斯大学医学中心人类研究对象委员会，和其他监督核查此研究项目的委员会以及办公室。

By signing this form, you are giving Dr. Susan Jackson and the research team permission to share information about you by posting the videotaped research session on the web for other researchers to study.
签署这份同意书，意味着您授权 Susan Jackson 博士以及此研究团队将您的研究录像放在网页上分享以供其他研究人员研究。还将意味着您授权此研究团队从您所在的医疗机构取得您的神经影像报告（脑部 CT 或者 MRI）

Some of the persons or groups who receive the health information may not be required by law to protect it. Once the information has been shared outside of KUMC, it might be disclosed by others and no longer protected by the federal privacy laws or this authorization. Your permission to use and share your health information will not expire unless you cancel it. Any research information that is placed in the medical record will be kept indefinitely.
一些收到这些健康信息的人员或者组织并不需要依据法律对此信息进行保护。一旦这些信息在堪萨斯大学医学中心外被分享，这些信息可能被其他人泄漏，也不再受到联邦隐私法或此知情书的保护。您对于使用和分享这些信息的许可和授权依旧有效，直到您终止许可为止。任何在医疗记录里的研究信息都会永久保存。

QUESTIONS
疑问

Before you sign this form, Dr. Susan Jackson or her associates should answer your question(s) to your satisfaction. If you have any more questions, concerns, or complaints after signing this form, you may contact Dr. Susan Jackson or one of her associates at (913) 588-5937. If you have any questions about the rights of research subjects, you may call (913) 588-1240 or write the Human Subjects Committee, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.
在您签署此知情书之前，Susan Jackson 博士以及她的同事会回答您所有的问题。假如在签署

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之后您有问题，关注，或者需要投诉，您可以拨打电话(913) 588-5937 联系 Susan Jackson 博士或者她的同事。如果您对于参与者的权利有任何疑问，请拨打电话(913) 588-1240 或者写信给人类研究对象委员会，地址为 Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160。

SUBJECT RIGHTS AND WITHDRAWAL FROM THE STUDY
参与者的权利和退出此研究项目

You may stop being in the study at any time. Your decision to stop will not prevent you from getting treatment or services at the University of Kansas Medical Center. The entire study may be discontinued for any reason without your consent by the investigator conducting the study. Participation can be discontinued by the investigator if it is felt to be in the participant's best interest or if the participant does not follow the study requirements.
您可以在任何时间退出此研究项目。退出此项目不会影响到您在堪萨斯大学医学中心接受的治疗和服务。此项目的研究员可以在未经您的同意下终止整个项目。研究员可以终止参与者的参与如果那是被认为对于参与者最好的决定，或者在参与者不遵守研究要求的情况下。

You have a right to change your mind about allowing the research team to have access to your health information. If you want to cancel permission to use your health information, you should send a written request to Dr. Susan Jackson. The mailing address is Dr. Susan Jackson, University of Kansas Medical Center, Department of Hearing and Speech, Mailstop 3039, 3901 Rainbow Boulevard, Kansas City, KS 66160.
您可以随时终止研究人员使用您的健康信息的许可。如果您想终止使用您健康信息的许可，您需要给 Susan Jackson 博士写一份要求信。她的地址是 Dr. Susan Jackson, University of Kansas Medical Center, Department of Hearing and Speech, Mailstop 3039, 3901 Rainbow Boulevard, Kansas City, KS 66160。

If you cancel permission to use your health information, you will be withdrawn from the study. The research team will stop collecting any additional information about you. The research team may use and share information that was gathered before they received your cancellation.
一旦您取消我们对于您的健康信息的使用权，您将被终止参与此项研究。研究团队届时也将停止对您的信息的收集。在收到您的取消书之前，研究团队将继续使用和分享收集到的您的信息。

CONSENT
同意

Dr. Susan Jackson and her associates have given you information about this research study.

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They have explained what will be done and how long it will take. They explained any inconvenience, discomfort, or risks that may be experienced during this study.
I freely and voluntarily consent to participate in this research study. I have read and understand the information in this form and have had an opportunity to ask questions and have them answered. **I will be given a signed copy of the consent form to keep for my records.**

Susan Jackson 博士以及她的同事已经将有关此研究项目的所有信息提供给我。他们解释了研究的步骤和时长。他们也解释了任何在研究当中可能出现的不便，不适，以及危险。我自愿同意参加此研究项目。我 已经阅读并且理解了此知情书上的信息，所提出的疑问也获得了解答。**我也将收到一份签署过的副本作为个人记录。**

_____
Type/Print Subject's Name参与者印刷体姓名

_____ _____ _____
Signature of Subject 签名 Time 时间 Date 日期

_____
Type/Print Name of Person Obtaining Consent 获得此知情书人的印刷体姓名

_____ _____
Signature of Person Obtaining Consent 签名 Date 日期

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