AphasiaBank Participants

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January, 12th, 2006

Dear Professor MacWhinney, Professor Holland,

First I would like to thank you for the invitation to join the consortium on your spontaneous speech project. We did quite some work on spontaneous speech analyses throughout the years, especially on Dutch, but some crosslinguistic comparisons between Dutch, English and Hungarian have also been made. We have data of hundreds of aphasic speaker (and dozens of normal speakers), which, however, need to be anonymized. These data are samples of at least 300 words spontaneous speech, elicited by standard questions (could you please tell how your speech problems started? can you tell me what kind of work you used to do? etc.). The data come from different aphasia types, but most are from speakers with Broca’s aphasia.

A couple of months ago, we decided to formalize the protocol, in collaboration with Gloria Olness. Apart from the standardized interview, we are using several pictures (among which the picture of Normal Rockwell and the cookie theft) and retelling of a fairy tale to find out which work best. What might be interesting for your project, is that we work on several languages: Dutch, German, Turkish, Italian and Russian and we are using the same procedure for all languages. Also, we have interview data of 40 aphasic speakers, unselected for aphasia type, of Frisian.

The goals of our current projects are to understand the underlying deficit in Broca’s aphasia, implying that we developed a number of tests for comprehension and production of sentences, with which we test individuals with Broca’s aphasia, but also with anomic and Wernicke’s aphasia for comparison. In one project we focus on phonological disorders, but the means of elicitation of spontaneous speech are the same as for the syntactic projects. Apart for this, we are running two treatment projects, one which also includes spontaneous speech before and after treatment and three month after treatment. So far, only individuals with Broca’s aphasia (n=6) have been included. These data can be made available for the project as well.

Since we test aphasic speakers in different languages, we cannot always use the same diagnostic tools. For Dutch and Italian we use the Aachen Aphasia test, for Turkish and Russian local aphasia tests. This is a problem that will be hard to overcome in crosslinguistic research, I am afraid. As mentioned above, we collect data from several languages, including language from minority groups in The Netherlands. These data have been collected from both ethnic groups in The Netherlands (who are usually bilingual and have been tested in both Dutch and their native language) and aphasic speakers living in their home country. It will not pose any problem to acquire two data sets from some aphasic speakers for reliability purposes.

All data have been audiotaped, there is only a very limited set of video-taped interviews. The reason is that we do not have the right equipment and we would be very grateful if the project can offer us this equipment. Of course, I would be delighted to get the opportunity to join the consortium meetings.

Yours sincerely,

Prof. Dr. Roelien Bastiaanse
Dept. Of Linguistics, University of Groningen
2. Albert, Martin

From: "Martin L. Albert" <malbert@bu.edu>
Date: January 16, 2006 10:26:20 PM EST
To: Brian MacWhinney <macw@mac.com>
Cc: audrey Holland <aholland@u.arizona.edu>
Subject: Re: invitation to join consortium

Hi Brian,

Happy to participate. Here are my (rather abbreviated) answers.  Good Luck,

Marty

Martin L. Albert, MD, PhD
Professor of Neurology
Director, Harold Goodglass Aphasia Research Center
Boston University School of Medicine

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?

Core neurological, neuropsychological, and neuroimaging data on large numbers of aphasic patients.

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.

Yes. Our Language in the Aging Brain group has been collecting discourse samples of various types on healthy elderly people for 25 years.

3. What are the goals of your current projects?

a.) explanation of lexical retrieval deficits in normal aging. b.) New treatment (metaphor training) for communication problems in right brain damage.

Do they include specific treatment approaches? Yes.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using. BDAE, BNT, ANT

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture
description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?

BNT, Cinderella, picture description

6. With how many subjects could you use this suggested shared protocol each year?

35-45

7. Would it be possible to test some patients twice in order to verify reliability?

Yes

8. How many of your patients are members of linguistic or ethnic minority groups?

10 - 15 %

9. Do you need any specific equipment support for videotaping?

Probably.

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?

Sure. Why not.
3. Armstrong, Beth

Brian MacWhinney, Ph.D.
Audrey Holland, Ph.D.
Psychology
Carnegie Mellon University
13th January, 2006

Dear Professors MacWhinney and Holland,

I wish to express my strong support for the proposal to be submitted to the NIH involving the development of a shared database of multimedia interactions for the study of communication in aphasia. Having discussed the project at length at the workshop “Collaborative Multimedia Analysis of Aphasic Communication” held at Carnegie Mellon in May 2005, I am convinced that this endeavour will be invaluable to ongoing research in aphasia internationally. The notion of a shared database will enable researchers to view the same data from multiple perspectives, encourage collaboration, and make maximum use of data provided by individuals with aphasia who wish to contribute to ongoing research.

In terms of my potential contribution to the project, I have outlined relevant points below in response to your initial queries:

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?

I have already contributed four audio recordings to the AphasiaBank database. These consist of interactions recorded between an individual with aphasia and his wife in their home. I also have further recordings from four other couples that I would be willing to contribute. In addition, I have a set of ten monologues that I would be able to contribute, consisting of stroke recounts. These are between 5-10 minutes each in length.

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.

Current research protocols involve:
   i) illness recount
   ii) happy experience recount
   iii) spontaneous conversation between person with aphasia and partner

3. What are the goals of your current projects? Do they include specific treatment approaches?

Current projects are concerned with exploring the ways in which individuals with aphasia use language to express opinions, and structure conversation. It is envisaged that
improving knowledge in these areas will lead to treatment approaches, but current projects are not focused on treatment.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.
   Boston Diagnostic Aphasia Examination (BDAE-3) (Goodglass, Kaplan, & Barresi)
   Psycholinguistic Assessments of Language Processing in Aphasia (Kay, Lesser & Coltheard, 1992).

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?
   We could incorporate all of the above.

6. With how many subjects could you use this suggested shared protocol each year?
   We are currently establishing a new clinic in which we could use the protocol, and we would anticipate between 10-15 new clients with aphasia each year.

7. Would it be possible to test some patients twice in order to verify reliability?
   Yes.

8. How many of your patients are members of linguistic or ethnic minority groups?
   This is difficult to say since our client base will be new. However, we would anticipate that around 30% of our caseload would fit into this category.

9. Do you need any specific equipment support for videotaping?
   A portable video camera would be required for obtaining data external to our on-campus clinic.

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?
    Yes.

Again, you have my fullest support for this important project.

Yours sincerely,

Elizabeth Armstrong PhD
Master of Speech & Language Pathology Course Coordinator,
Macquarie University,
North Ryde,
Sydney, Australia.
4. De Bleser, Ria

From: Ria De Bleser <debleser@ling.uni-potsdam.de>
Date: January 18, 2006 9:59:33 AM EST
To: macw@mac.com, aholland@u.arizona.edu
Subject: Re: invitation to join consortium
Reply-To: debleser@ling.uni-potsdam.de

Dear Audrey, dear Brian,

We welcome your initiative very much and are willing to join with whatever we can contribute. Our answers to your questions:

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?

The spontaneous speech data we have from our aphasia patients (audio) were so far given with the patients' consent for internal use in our teaching and research programme, not for world-wide dispersion, so we could only contribute with new data which are given with this more general consent. The same applies to the points below. So far, we collected spontaneous speech of patients every 14 weeks, so we do have repeated and recovery samples of our patients. The procedure for analysis follows the Aachen Aphasia Test guidelines.

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.

We have a refined linguistic analysis of agrammatic speech, but again consent was only given for the particular research project. We also have a detailed analysis of cookie theft in German normals, demented and aphasic subjects.

3. What are the goals of your current projects? Do they include specific treatment approaches?

We investigated the effects of syntactic production therapy in agrammatic subjects following TUF of C. Thompson on spontaneous speech and also of lexical treatment in anomic subjects.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.

We use LeMo, a test we developed to discover the functional deficit in patients.
and which is similar to PALPA but much easier to analyse since it is computer-assisted. We also use the Aachen Aphasia Test (AAT) for clinical screening.

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?

Routinely, we only have data from a semi-standardized interview.

6. With how many subjects could you use this suggested shared protocol each year?

If we include the institutions where our graduates work, it could be approximately 100/year.

7. Would it be possible to test some patients twice in order to verify reliability?
Yes.8. How many of your patients are members of linguistic or ethnic minority groups?
Very few.

9. Do you need any specific equipment support for videotaping?
No.

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?
Yes, Henrik Bartels would be responsible for this area.

Best wishes,

Ria

Prof. Dr. Ria De Bleser
Department of Cognitive Neurolinguistics
(www.ling.uni-potsdam.de/patho)
Coordinator Erasmus Mundus EMCL program
(www.emcl-mundus.com)
Dean of the Faculty of Human Sciences
(www.uni-potsdam.de/fakultaeten/hum)
University of Potsdam
PF 601553
Dear Drs. MacWhinney and Holland:

I strongly support your proposal to NIH for developing and maintaining a system for sharing multimedia data from aphasic participants. A common database accessible to researchers with differing perspectives and distinct goals will be a powerful source for broadening and deepening our understanding of the nature of aphasic communication problems and ways to treat them. It will certainly be an extremely valuable resource in my own work, which focuses on assessing and treating word retrieval impairments in discourse.

Following are specific ways that I might contribute to the project:

1. Pending approval of my university’s IRB, I can contribute audio and video recordings, and their transcripts, of persons with aphasia performing discourse tasks and standardized tests, outlined below.

2. My current research protocol to collect discourse samples uses the Nicholas and Brookshire discourse tasks published in their 1993 paper in the *Journal of Speech and Hearing Research* (Vol. 36, pp.338-350). There are ten tasks: description of four complex pictures (the Cookie Theft, the picnic scene from the WAB, a birthday party, and a cat being rescued from a tree), two picture sequences (one depicts a couple’s argument and its aftermath; the other shows a couple getting directions that don’t work out); two procedural questions (how to write a letter and how to do dishes by hand), and two personal questions (describe where you live; tell what you usually do on Sundays).

3. My current projects focus on assessing and evaluating a treatment for word retrieval problems in a discourse context. I have adapted semantic feature analysis as a treatment that is used as participants produce narratives about wordless picture stories. Concurrently, I am investigating the reliability and validity of methods to assess word retrieval impairment in discourse, since current standardized assessments
only test in a confrontation naming context. I am also collaborating with a neurologist in a study assessing pharmacological intervention for aphasia.

4. The standardized assessments that I currently use are the *WAB*, portions of the *BDAE*, the *CADL-2*, the *Test of Adolescent/Adult Word Finding*, and the Nicholas and Brookshire procedures for correct information units and main concepts. I also use a modified version of German’s *Test of Word Finding in Discourse*.

5. I can adopt all of the elements of the shared protocol that you are proposing. Are you proposing to elicit the Cinderella story retell using a picture book with the words covered? If so, I suggest that you provide every member of the consortium with the same book with which to elicit this story, or at least give us the publication information so that we can all purchase the same book. A few years ago, I participated in a multi-center treatment research study that used this task. They provided different Cinderella picture books to the different sites. The protocol specified that the participants should look through the books before beginning their narratives in order to refresh their memories about all the episodes of the story. However, because the illustrations were not uniform among the sites, we could not be certain that each participant had the same opportunity to produce all the themes and details in the story, since different artists depict different items and scenes. Similarly, Norman Rockwell pictures are available in all sizes. I’ve seen some that are really quite small (taken from desk calendars), which might make it difficult to see the details important to a narrative elicitation. Therefore, some guidelines on the appropriate size of these materials (if we are to find them ourselves) would be useful.

6. I could use the proposed protocol with a minimum of 10 patients each year, possibly more.

7. I would probably be able to test most patients twice to verify reliability.

8. In recent projects, 25% to 30% of my participants were members of minority groups.

9. I use my department’s digital camcorder and my own wireless external microphone for my on-campus research projects. For my collaborative project with the neurologist, we use the hospital’s Hi-8 videocamera. I have found the Hi-8 format to be problematic, since it is not compatible with standard VHS playback systems (i.e., the videos must be viewed at the hospital on their equipment). I am not able to take the university department’s digital camcorder to the hospital, since it must be available for other faculty and staff to use. If the consortium could provide a videocamera for me to use at the hospital, it would be much easier to include participants from that project in the data collection.

10. I would be very interested in participating in yearly consortium meetings. I believe my research agenda would benefit tremendously from such collaboration.
Thank you for inviting me to participate in this important project. Please let me know if I can assist in development of the proposal in any way.

Sincerely,

Mary Boyle

Mary Boyle, Ph.D., BC-NCD
Associate Professor and Graduate Advisor
Department of Communication Sciences and Disorders
President, Academy of Neurologic Communication Sciences and Disorders
Dear Dr. MacWhinney and Dr. Holland,

I have reviewed a draft of your NIH grant proposal regarding the construction of a shared database of multimedia interactions for the study of communication in aphasia. I am extremely excited about the prospect of having a standard protocol for recording, transcribing, coding and analyzing the communication of people with aphasia. The availability of such tools, together with the construction of a shared data base of the resulting multimedia interactions, will go a long way to helping us understand the nature of the language impairment in aphasia. In regards to my own personal work in the field, the support provided by such a project will certainly help us to evaluate, both quantitatively and qualitatively, the efficacy of specific treatment interventions for aphasia.

At the present time, I have data (on both audio and videotapes) collected from several completed and ongoing treatment intervention studies that could be contributed to AphasiaBank. All these studies include comprehensive pre- and post-treatment assessments of communication. The standardized assessment instruments that I have been using are primarily the Western Aphasia Battery, the Boston Naming Test, and the Communication Activities of Daily Living (2nd edition). Interestingly, the discourse elicitation tasks that I have been using already include many of those that you are proposing: the Cinderella story; the cookie theft picture description; narrative picture descriptions; and some free speech samples. As you know, discourse transcription and analysis is a very time-consuming and tedious process, so the assistance that you are proposing for contributors to the AphasiaBank will be invaluable.

Here is a list of the grants in which pre- and post-treatment data is collected on individuals with aphasia, and for which I am the Principal Investigator and have control over the use of the data:


AphasiaBank Participants

National Institute on Disability and Rehabilitation Research (NIDRR). Computerized Training of Conversational Scripts to facilitate Integration into the Community and Work Force. Part of the RRTC Grant on Stroke. 10/1/03 – 9/30/08.

National Institutes of Health (NCMR). R21. Effects of Bromocriptine on Aphasia Treatment Outcome 1/1/02 – 8/31/06


The above studies have been conducted at the Rehabilitation Institute of Chicago which is a large urban free-standing rehabilitation center. As such, the subjects reflect the ethnic make-up of the Chicagoland area and do include African-American and Hispanic subjects.

I should also mention that when you expand the AphasiaBank to other subject groups, I will be able to contribute discourse samples on patients with right hemisphere cognitive-communication disorders. These are primarily audiotapes and were collected during several studies conducted between 1990 and 2002.

Thank you for the invitation to participate in this innovative and worthwhile project. I heartily endorse it and hope that funds will soon be available to support it.

Sincerely,

Leora Cherney, Ph. D.

Clinical Research Scientist
Center for Aphasia Research
Rehabilitation Institute of Chicago.

Associate Professor, Physical Medicine and Rehabilitation
Feinberg School of Medicine, Northwestern University.
7. Coelho, Carl

From: "Coelho, Carl" <carl.coelho@uconn.edu>
Date: January 16, 2006 2:57:15 PM EST
To: Brian MacWhinney <macw@mac.com>
Subject: AphasiaBank

January 16, 2006

Brian MacWhinney, Ph.D.
Psychology Department
Carnegie Mellon University

Dear Professor MacWhinney:

I am very pleased to hear of your plans to submit an NIH proposal to develop and support an archive of multimedia language data from individuals with aphasia. I have studied discourse deficits subsequent to brain injuries for many years. In that time it has been difficult to compare my findings to those of other investigators because of the varied language elicitation and analysis procedures employed. Establishing a consortium of researchers interested in aphasia discourse and employing similar methodologies would greatly facilitate our understanding of language disruption in aphasia and how to best manage such communicative impairments.

I have summarized my responses to the questions you posed pertaining what my colleagues and I, at the University of Connecticut, may be able to contribute to this project.

Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you briefly describe these data? I have numerous discourse samples from individuals with brain injuries, most of which are audio recordings. I do have a variety of video recordings from aphasia groups that may be suitable for inclusion in AphasiaBank.

Do you or your research group have any ongoing research
protocols that collect discourse samples? Please provide a brief description of the protocols. We are currently studying discourse impairments following penetrating head injuries. Protocol involves a story retell task and segments of conversational speech extracted from an intake interview which begins with the question “How has your head wound changed your life?”

0. What are the goals of your current projects? Do they include specific treatment approaches? The primary goals are to associate discourse deficits with lesion data including size and specific locale (Brodmann areas) and thus have a clearer understanding of how discourse is organized in the brain. We are also interested in identifying discourse analysis procedures which can yield the greatest amount of clinically useful information for the time invested.

0. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using. We employ the Boston Naming Test, the Token Test, the Discourse Comprehension Test, portions of the Delis-Kaplan Executive Function System, Happe Stories, Wais-III, and a variety of other cognitive measures.

0. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered? I would be happy to adopt this protocol for the individuals in our aphasia group. The protocol for the individuals with penetrating head injuries cannot be changed. I would advocate for the use of Rockwell pictures over the Cookie Theft as I believe those pictures generally elicit a more complex story.

0. With how many subjects could you use this suggested shared protocol each year? 20-25 individuals with aphasia per year.

0. Would it be possible to test some patients twice in order to verify reliability? Yes

0. How many of your patients are members of linguistic or ethnic minority groups? Less than 5 percent.
0. **Do you need any specific equipment to support videotaping?** A digital videocamera would be very helpful.

0. **Would you be interested in being invited to participate in yearly consortium meetings?** Yes.

Thank you for the opportunity to contribute to this very important and exciting project. Feel free to contact me should you need any additional information.

Sincerely,

Carl A. Coelho, Ph.D.
Professor and Head
Communication Sciences Department
University of Connecticut
Storrs, CT 06269-1085
8. Elman, Roberta

January 14, 2006

Brian MacWhinney, Ph.D.
Department of Psychology 254M Baker
Carnegie Mellon University
5000 Forbes Ave.
Pittsburgh, PA 15213

Dear Dr. MacWhinney:

It would be my pleasure to become a member of the consortium that is detailed in your proposal to NIH entitled, “AphasiaBank: A Shared Database for the Study of Aphasic Communication.” Systematic study of the speech and language of individuals with aphasia has critical clinical applications for the millions of individuals worldwide living with this disorder. I look forward to working with you and other consortium members in furthering the knowledge base. I’ve provided answers to your set of questions below. Please do not hesitate to contact me if you need additional information.

Roberta J. Elman, Ph.D., CCC-SLP
President & Founder, Aphasia Center of California
Board Certified—Academy of Neurologic Communication Disorders & Sciences
Fellow, American Speech-Language-Hearing Association

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?

We have a set of unanalyzed discourse measures collected for our efficacy study on Group Communication Treatment for individuals with chronic aphasia (Elman & Bernstein-Ellis, 1999). The discourse data were collected in 1994-1996 and were collected by “camcorder” and stored on ½” videotapes. Discourse measures included the following: connected speech measures (Nicholas & Brookshire, 1993), conversation with a significant other following viewing of a feature television segment, and interviews with participants and their significant others about the “positives” and “negatives” of being in the group treatment program. We used a repeated measures design, so these data were collected at intake, after two months of group communication treatment, after 4 months of group communication treatment, and at follow-up, about 6-8 weeks later.

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.

We do not have any current research protocols.
3. What are the goals of your current projects? Do they include specific treatment approaches?

The Aphasia Center of California uses a Life Participation Approach to Aphasia (2001) in its community-based program. Current treatments include nine weekly communication groups, the Book Connection™ aphasia book club program, individual speech-language treatment, a caregivers’ group, a quarterly educational series about stroke, and recreational classes. Participants individualize a program from this array of services.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.

We do not have any research protocols using standardized assessments at this time.

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?

We could adopt the proposed protocol. We would also suggest including a conversational speech task.

6. With how many subjects could you use this suggested shared protocol each year?

This would depend on external and internal funding. We see approximately 100 people with aphasia each year at the Aphasia Center of California.

7. Would it be possible to test some patients twice in order to verify reliability?

Yes, depending on external and internal funding.

8. How many of your patients are members of linguistic or ethnic minority groups?

Our clients are all English speaking. Ethnicity reflects the diversity of the San Francisco Bay Area as we have African American, Hispanic, Asian and Caucasian participants.

9. Do you need any specific equipment support for videotaping?

Yes, we would need equipment to support videotaping.

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?

I would be extremely interested in being invited to participate in the yearly consortium meetings.
Dear Drs MacWhinney & Holland,

It was very exciting to hear that you are developing a proposal to NIH to support a system for sharing multimedia data from aphasic participants. I was fortunate in hearing the very positive feedback and information from Dr Beth Armstrong and Dr Leanne Togher who attended the May 2005 ‘Collaborative Multimedia Analysis of Aphasic Communication, as they are colleagues within our Clinical Linguistics Research Group (a cross-institutional research group comprising speech pathology researchers from University of Newcastle, University of Sydney, Macquarie University and Charles Sturt University in New South Wales, Australia). The project has the potential to greatly increase the power of the research currently being done into aphasic communication, and thus to increase the generalisability of findings to the wider population of people with aphasia. I would be very pleased to be a participant in the consortium that you proposal. I have addressed each of the specific questions that you circulated, with reference to my current research.

1. *Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?*

I have two data sets which may be potentially available to contribute to the AphasiaBank. The first data set comprises conversational interactions between ten people with chronic mild-moderate fluent aphasia, a familiar and a less familiar partner. The second data set comprises personal recount from ten people with chronic aphasia (2 non-fluent, 8 fluent) on two occasions (approx. 3 months apart). Ethics clearance for use of these data sets would need to be obtained, as permission for archival/corpus use was not originally sought from the research participants. For over half of these research participants it will not be possible to obtain direct consent, since contact has been lost with these individuals.

2. *Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.*
The research protocol I am currently using comprises the following discourse sampling research protocol: Personal recount; Conversational interaction with familiar partner - audiotaped, transcribed, SALT analyses (Miller, 2003), Systemic Functional Linguistic analyses (Halliday & Matthiessen, 2004).

3. What are the goals of your current projects? Do they include specific treatment approaches?
The goals of my current projects are, firstly, to identify how might we validly sample natural communication interactions involving people with aphasia, and secondly, to identify and describe what can make communication more effective in these interactions. My current projects do not involve research investigating specific treatment approaches.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.
My current research protocol includes the following standardized assessments:
• Boston Aphasia Diagnostic Aphasia Examination (BDAE) – Aphasia Severity Rating Scale & Rating Scale Profile of Speech Characteristics
• Communicative Effectiveness Index (CETI) – Lomas et al (1989)
• Visual Analogue Self-Esteem Scale (VASES) – Brumfitt & Sheeran (1999)
• Dartmouth COOP Functional Assessment Charts (van Weel et al, 1995)

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions.
Which of these components can you adopt? What additional components do you believe need to be considered?
All of these components can be adopted into prospective data collection. I would strongly urge the inclusion of conversational interaction between the person with aphasia and a familiar partner who is NOT a speech-language pathologist or other health professional. Although there is potential for greater variability in this type of sampling, this is outweighed in my opinion by the greater validity of the sample. When such samples are available along with more standardized sampling methods, then I think they add greatly to the scope of research.

6. With how many subjects could you use this suggested shared protocol each year?
I have access to an aphasia therapy group program which would allow for 10 new subjects each year who would be suitable for the shared protocol.

7. Would it be possible to test some patients twice in order to verify reliability?
From our experience over the last two years with this aphasia therapy group program, it would be possible to re-test 3 of these 10 subjects per year in order to verify reliability (restricting re-testing to those with chronic aphasia without significant changes in health status over the year).

8. How many of your patients are members of linguistic or ethnic minority groups?
None of our patients are members of linguistic or ethnic minority groups. With specific funding support, it would be possible to seek to identify a small number, perhaps up to 3 per year in our regional area from other linguistic or ethnic minority groups.

9. *Do you need any specific equipment support for videotaping?*
No equipment needed. We have access to digital video and audiotaping facilities.

10. *Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?*
Yes, I would be very interested in be invited to participate in these meetings, and funding support would greatly assist participation.
Thank you for your invitation to participate in this project. Please don’t hesitate to let me know if any further assistance or information is required.

Regards,

Alison Ferguson, PhD
Associate Professor in Speech Pathology
Speech Pathology Discipline & Program Convenor
10. Hengst, Julie

From: "Julie A. Hengst" <hengst@uiuc.edu>
Date: January 15, 2006 1:13:21 PM EST
To: Brian MacWhinney <macw@mac.com>
Subject: Letter of support

Dear Drs MacWhinney and Holland,

I am writing to accept your invitation to participate in the proposed AphasiaBank project, a shared database of multimedia data including discourse samples from individuals with aphasia. I strongly support these efforts and feel that the development of such a database will contribute significantly to ongoing research into the nature and impact of aphasia, as well as supporting important pre-service and in-service pedagogical goals. Making this database available to a consortium of clinical researchers, both in seeking contributions to the database and accessing it as a data source, will greatly enhance its breadth and usefulness.

To support the NIH application funding for the AphasiaBank project, your invitation requested specific information about my current and future research plans and how they might intersect with, and/or support, the AphasiaBank project. I will devote the remainder of this letter to those issues.

Broadly, my research draws on ethnographic and situated discourse analysis approaches to study the communicative practices of individuals with neurogenic communication disorders (primarily aphasia) and their routine communication partners. Currently, I have been conducting ongoing analyses of several existing data sets, none of which are in a form that I could contribute to AphasiaBank. At this time I am not enrolling new participants in research projects; however, I plan to initiate a new study in 2007 that would include ongoing enrollment. It should be very feasible to include a data collection phase in that protocol that would support both my immediate project and obtain data to include in AphasiaBank. Depending on funding support, I anticipate this project enrolling from 3-9 participants a year for 3 years. In addition to that project, given that I work at UIUC, which has a training clinic, I would also be glad to explore the possibility of seeking enrollment of appropriate clients from our clinic roles specifically for AphasiaBank. Finally, based on my current datasets and clinic clients, participation from minority groups is small, approximately 5-10%.

The data collection protocols I use vary with the needs of the research project, including minimally structured sampling (e.g., community observations of individuals with routine partners), more structured sampling (e.g., barrier task protocols), discourse elicitation procedures (e.g., conversational, narrative, procedural, picture description samples), and
formal testing (e.g., BDAE). Clearly, there are many benefits of using a common data collection protocol for AphasiaBank. In order to collect data for AphasiaBank using the common protocol, I would need approval from UIUC’s IRB for informed consent procedures, participants would need have to be willing sit for the additional testing and allow it to be used in AphasiaBank, and I would need to have sufficient resources to devote to this data collection. Generally, I would not anticipate problems meeting these requirements and would be glad to collect data for AphasiaBank under these conditions.

Given the nature of my research, I already have recording equipment (mini-DV camera and playback; analog audio recording and playback). However, I may need equipment support to meet specific format requirements for AphasiaBank, and/or to manage equipment failure problems at points when I do not have other funding. In addition, one of the great benefits of working on consortium-based projects such as AphasiaBank is the opportunity they provide for discussions with other researchers in the field. Therefore, I would be very interested in participating in yearly consortium meetings.

Again, thank you for including me among the researchers you invited to participate in the AphasiaBank consortium. If I can be of any further help at this time, please don’t hesitate to contact me.

Sincerely,

Julie A. Hengst, Ph.D.
Department of Speech and Hearing Science
University of Illinois at Urbana-Champaign
Champaign, IL 61820
Tel: 217-244-6149
Email: hengst@uiuc.edu
11. Hinckley, Jacqueline

To: Brian MacWhinney and Audrey Holland

From: Jacqueline Hinckley, Associate Professor
Communication Sciences & Disorders
University of South Florida, Tampa, FL, USA

Date: January 15, 2006

Re: Proposal

Thank you for the opportunity to provide my enthusiastic support for the project proposed by Drs. MacWhinney and Holland regarding the Aphasia TalkBank project. This project will serve to help standardize and collect similar types of discourse samples across a variety of research projects. The ultimate contribution of such a large-scale project will be to understand the implications for conversation and other everyday forms of communication of different types of aphasia and different types of aphasia treatment.

I am pleased to offer my support for this project and would enthusiastically participate. I summarize the data I can provide to such a project in the responses to specific questions below.

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data? *YES. I have discourse samples from approximately 60 adults with aphasia due to stroke. The samples include conversation, story retelling, and procedural narratives.*

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols. *At the moment I am between research protocols but hope to receive funding for an aphasia treatment project that will collect discourse samples from approximately 20-30 additional participants with aphasia.*

3. What are the goals of your current projects? Do they include specific treatment approaches? *The goal of the project for which data has already been collected was to compare two different approaches to aphasia treatment and to compare outcomes as they relate to the underlying theoretical foundations. The goal of the upcoming project is explore outcomes, including discourse, of exercise-enhanced language stimulation treatment for aphasia in a safety and feasibility study.*

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using. *My previously collected data include results from the CADL-2, subtests of the PALPA, and BDAE. Our upcoming project will include results from the WAB and CADL-2. In regards to discourse samples, my...*
protocol has included: free conversation, Cookie Theft picture description, Cinderella story retelling, and procedural discourse including how to make toast and how to get groceries.

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered? I routinely use almost all of these with the exception of the BNT, but I would happily include the BNT to any protocol.

6. With how many subjects could you use this suggested shared protocol each year? Approximately 15-20.

7. Would it be possible to test some patients twice in order to verify reliability? Yes, a baseline re-testing is part of our upcoming protocol.

8. How many of your patients are members of linguistic or ethnic minority groups? Approximately 20-30% of our patients are members of minority groups, including African-Americans and Latino groups.

9. Do you need any specific equipment support for videotaping? No. Our lab is currently equipped with digital video arrangements.

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)? Yes, I would be thrilled to do so.
I am writing to provide enthusiastic support for the development of a multimedia data-
base for collecting and sharing data amongst a consortium of international researchers
committed to the study of communication difficulties associated with aphasia and
associated neurogenic disorders. I am particularly supportive of the application for
NIH funding to enable the development of resources that will ensure the systematic
collection and analysis of speaking samples. A larger pool of data from a variety of
countries will enhance the scientific strength of the studies and ensure that the impact
of results is far reaching.

My responses to the series of questions designed to establish the links with my own
research are as follows:

1. Do you have any existing data that you would be willing to contribute to
AphasiaBank? If so, could you please briefly describe these data?

My research group has been committed to the analysis of discourse for a number of
years. I would be willing to contribute discourse samples where appropriate consent has
been given. We have collected conversational samples from normal participants and
people with right hemisphere disorder, William’s syndrome, acquired aphasia, primary
progressive aphasia and dementia. In addition we have samples from bilingual speakers
both in their first and second languages. In addition to conversation we have collected;
autobiographical monologues, picture descriptions, procedural narratives, and
spontaneous samples in response to a variety of verbal and pictorial prompts designed to
elicit a range of emotions and cognitive load.

I am happy to ensure that all future samples will be include consent for inclusion in the
database.

2. Do you or your research group have any ongoing research protocols that collect
discourse samples? Please provide us a brief description of the protocols.
We have used a standard set of stimuli for several projects. This includes responses to the question “what did you do yesterday?”, the cookie theft picture description, and description of “far side” cartoons which do not include text. These cartoons are abstract and quite cognitively demanding. The participants found them engaging.

3. What are the goals of your current projects? Do they include specific treatment approaches?

Our current research focuses on the segmentation of discourse using a boundary threshold of 20msec followed by application of a MATLAB algorithm to characterize the pause and speech duration distributions for the sample. We are currently investigating the impact of genre on the pause distributions as well as reliability of pause measurement. In addition we are conducting perceptual judgment studies to investigate the relationship between listener judgment and objective measurement of fluency. We then conduct intentional, informational and structural analyses of the segments. We are currently planning a treatment study.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.

Use of standardized tests depend on the particular population under investigation. They include, BDAE, and some traditional neurpsychological tests. We also use the CIU analysis, Coherence analysis, and SALT.

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?

We could use all of the tasks suggested. We would prefer a variety of genres for free speech sampling and multiple examples of each genre particularly as we conduct multiple assessments.

6. With how many subjects could you use this suggested shared protocol each year?

Approximately 200 (if we are successful in obtaining some further funding) sessions although this could include multiple testing on a sample of participants.

7. Would it be possible to test some patients twice in order to verify reliability?

Yes but we prefer to test approximately 8 times in order to obtain measures of change and stability.

8. How many of your patients are members of linguistic or ethnic minority groups?
Approximately 30%.

9. Do you need any specific equipment support for videotaping?

*We would be very interested in using standard microphones and digitizing and storage formats.*

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?

*Most definitely. There are many issues to discuss in this field and an opportunity to demonstrate and discuss is essential for progress progress in this domain.*

Thankyou so much for the opportunity to be part of this timely and important initiative. Please let me know if I can assist further.

Your sincerely,

Kathryn Hird PhD FSPA MAPS
13. **Holland, Audrey**

**From:** audrey Holland <aholland@u.arizona.edu>
**Date:** January 17, 2006 7:21:05 PM EST
**To:** Brian MacWhinney <macw@mac.com>
**Subject:** Re: letter

Dear Brian,

You know already that I have been associated with CHILDES and TalkBank since their inceptions and that I truly respect and care about their importance. Also, since their beginning, I have believed that this effort could move on ultimately to influence our understanding and of aphasia and its management. I am thrilled to be a part of this proposal.

Thank you so much for making me a part of it.

Sincerely,

Audrey L. Holland, Ph.D.
Regents' Professor Emerita
University of Arizona.
Dear Audrey, dear Brian,

Thank you very much for your important initiative and your kind invitation to join the proposed consortium. Indeed, an efficient and detailed analysis of spontaneous language is a long needed goal of aphasia research, which many groups worked on in the past but which to my knowledge was never convincingly solved. Under the perspective of aphasia rehabilitation, changes in spontaneous language are likely to reflect both changes in the underlying language deficit as well as in adaptation to the deficit. Having enough samples under well controlled conditions of elicitation available - as you propose - will provide the opportunity to disentangle aspects of impairment and participation that may lead to changes in the course of aphasia. At the same time, comparison with changes in first and second language learning of non-brain damaged speakers would be most instructive to gain insight into possible mechanisms of language reorganisation and plasticity of the human brain.

With these general remarks in mind, we are pleased to answer your questions as follows.

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?

We have spontaneous speech data from fluent and non-fluent aphasic patients (audio-tape and wave-files) in different stages of recovery (acute, postacute, chronic), transcribed using our own system (Aachener Sprachanalyse, ASPA).

ASPA is less refined than CHILDES. It requires an PC assisted orthographic transcription with the help of visualized sound wave information. For linguistic analysis, the examiner has to segment the running speech into conversational turns and syntactic phrases. The lexical identification of utterances is done automatically, which has to be controlled by the examiner. As final result, ASPA provides statistical information about basic parameters of syntax, lexicon and prosody. The system is specifically developed for German. Our validation studies have demonstrated that speech output of speakers with different standard syndromes of aphasia can be reliably discerned from each other as well as from normal speakers.

2. Do you or your research group have any ongoing research protocols that collect...
discourse samples? Please provide us a brief description of the protocols.
We collect speech samples at the beginning and end of a seven-week intensive language therapy. The elicitation style is taken from the Aachen Aphasia Test (AAT). The treatment takes place on a specialized Aphasia Ward of the Aachen University hospital; the participants are inpatients.

3. What are the goals of your current projects? Do they include specific treatment approaches?
We investigate changes in spontaneous speech abilities after intensive language treatment in general (no specific treatment approaches at the moment) in order to establish a set of basic parameters for clinical diagnostic purposes. More specifically, we try to assess psychometrically for each individual participant whether the changes between two examinations are larger than the variability within the same examination. In addition, we compare the results with the standardized AAT scores derived from auditory ratings of aphasic symptoms observed in spontaneous speech.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.
We are using the Aachen Aphasia Test (AAT) (including a semi-standardized interview) and the Amsterdam-Nijmegen-Everyday-Language-Test (ANELT).

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?
Since we have only German speech samples, we don't use WAB and BNT but comparable ones (AAT). We can adopt Cinderella and picture description as well as a new standard set of elicitation questions.

6. With how many subjects could you use this suggested shared protocol each year?
Depending on the inclusion criteria up to 80 patients.

7. Would it be possible to test some patients twice in order to verify reliability?
Yes. See answers to 2 and 3.

8. How many of your patients are members of linguistic or ethnic minority groups?
Very few. Nearly all are caucasian native speakers of German (appr. mean age of 50 with a range of 20 to 70). About 50% have reasonable premorbid L2 competence of English and/or other European languages. Fully multilingual aphasic subjects are the exception.

9. Do you need any specific equipment support for videotaping?
No. We currently don't use video - but only audiotapes. Video recording could be done in
cooperation with our multimedia center.

**10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?**

Definitely yes, especially if German data would be also of interest for the members of the consortium. My collaborators are Marion Grande PhD and Katja Hussmann MA.

Thank you again for taking the initiative and considering us in this new project.

With kind regards,

Walter

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Walter Huber PhD
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15. Jackson, Susan
January 13, 2006

Dear Drs. MacWhinney and Holland:

I would be most happy to be a member of the AphasiaBank consortium, and I am willing and able to contribute language samples from individuals with aphasia to this database. I am a licensed and certified speech-language pathologist. I evaluate and treat individuals with aphasia as part of my clinical teaching responsibilities as a faculty member in the Hearing and Speech department at the University of Kansas Medical Center. I have existing written and audiotape recorded language samples from persons with aphasia that were gathered during individual clinical evaluations and treatment sessions and also from group treatment sessions that I could contribute to AphasiaBank. I do not have any ongoing research protocols that collect discourse samples. Most of my current research is with individuals who have dementia rather than aphasia, and I have submitted two grants in the last three months in an attempt to secure funding for two projects involving persons with Alzheimer’s disease (AD). One project has major emphasis on the evaluation of persons with AD, and the other one is a treatment study (medication plus cognitive-communicative stimulation). I do not have any ongoing research protocols that include standardized assessments, but I use standardized assessments in the clinical evaluation of individuals with aphasia (Western Aphasia Battery, Boston Diagnostic Aphasia Examination, Boston Naming Test, Discourse Comprehension Test, Aphasia Diagnostic Profiles, Communication Abilities in Daily Living). I think that the shared protocol that you are proposing will yield useful information about the expressive language skills of individuals with aphasia; I can adopt all of the components of the protocol in evaluations of individuals with aphasia. I believe that a measure or two to assess the pragmatics of language would provide a more comprehensive picture of aphasic language. I could use this shared protocol with approximately 20 subjects with aphasia per year. It would be possible for me to test some of the subjects twice in order to verify reliability. I do not tend to see many individuals with aphasia who are members of linguistic or ethnic minority groups, but there are relatively large Black and Hispanic populations in the Greater Kansas City Metropolitan Area; with a little effort, I would estimate that 20% of the persons with aphasia with whom I could use the shared protocol annually would belong to a linguistic or ethnic minority group. I would not need any specific equipment for videotaping; our university clinic has just purchased state-of-the-art video and recording equipment. I would be interested in participating in yearly consortium meetings.

I wish you success with this grant submission!

Sincerely,

Susan T. Jackson, Ph.D., L/CCC-SLP
Associate professor
16. **Kempler, Dan**

January 9, 2006

Dear Drs. MacWhinney and Holland:

I am writing to offer my full support for your upcoming NIH grant application to support the development of the AphasiaBank database for study and sharing of multimedia data from individuals with aphasia. The workshop that I attended last spring on the topic was inspiring and the AphasiaBank database will be an incredible asset to research in this area. I will address each question you posed below.

1. **Existing data to contribute to AphasiaBank:** I have contributed several videos and transcripts of adults with language disturbance due to dementia. In addition to those data, I have several videotapes of adults with aphasia that I could contribute as well.
2. **Ongoing research protocols collecting discourse samples:** During the past six months I have collected discourse samples from one individual with aphasia before, during and after intensive language therapy. These samples could be contributed.
3. **Goals of current projects:** pilot study on the efficacy of intensive language therapy during the chronic stages of aphasia.
4. **Standardized assessment included in protocol:** BDAE
5. **Suggested components that we could adopt:** all of them
6. **How many subjects could we share each year:** 1 or 2
7. **Is it possible to test patients twice in order to verify reliability:** yes
8. **Minority groups:** none represented at this point
9. **Equipment needed to support videotaping:** we have VHS equipment available.
10. **Interest in participating in yearly consortium meetings:** yes

Please let me know if I can be of any further assistance.

Best of luck,

Daniel Kempler, Ph.D./CCC
Professor and Chair
Communication Sciences and Disorders
Emerson College
120 Boylston St.
Boston, MA 02116
17. Kiran, Swathi

From: Swathi Kiran <s-kiran@mail.utexas.edu>
Date: January 9, 2006 7:49:48 AM EST
To: Brian MacWhinney <macw@mac.com>
Cc: aholland@u.arizona.edu
Subject: Re: invitation to join consortium

January 9, 2006

Dear Drs. MacWhinney and Holland:

Thank you for the invitation to participate in the AphasiaBank project. By way of this email, please consider my acceptance to participate in this important and timely project. I believe that the AphasiaBank will have a profound impact on the way we conduct aphasia research and its interpretation. My research involves treatment for lexical retrieval deficits in patients with aphasia. As part of our research protocol, we collect data from standardized tests and narrative tasks in order to assess treatment induced changes during language production.

I have responded to your questions so as to provide a comprehensive view of the way my research data could contribute to the AphasiaBank.

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data? Yes, there is data from two treatment studies (8 patients). These include pre-post standardized test assessments (WAB, BNT, PALPA) and narrative discourse.

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.

Currently, two treatment studies examine the effect of typicality treatment on lexical retrieval in patients with aphasia. Participants receive a set of standardized assessments prior to and following treatment. Treatment is a semantic featured based naming treatment exploiting typicality of category examples. Narrative discourse is collected before and after treatment. This data includes Cinderella story retell and WAB picture description. The tapes are transcribed but not analyzed or coded for any specific information.

3. What are the goals of your current projects? Do they include specific treatment approaches? Yes, my current projects employ typicality treatment within semantic categories to
examine semantic complexity, following the CATE hypothesis (Thompson et al., 2003). Another treatment study examines cross linguistic generalization in English-Spanish patients with bilingual aphasia.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.
There are three treatment projects all of which include standardized assessments. In the monolingual aphasia studies (N= 2), the standardized assessments include Western Aphasia Battery, Boston Naming Test, PALPA, Pyramids and Palm Trees Test, and Cinderella Narrative Task. In the bilingual aphasia treatment study, the standardized assessments include Western Aphasia Battery, Boston Naming Test in English and Spanish, Bilingual Aphasia Test in English and Spanish, PALPA, and Cinderella Narrative Task.

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?
We are already using the WAB, BNT, Cinderella story retell task. I would be happy to incorporate a free speech sample based on a standard set of elicitation questions.

6. With how many subjects could you use this suggested shared protocol each year?
Approximately 9-12/year. I also have approximately 50 patients registered in the aphasia research laboratory who have participated in research projects in the past.

7. Would it be possible to test some patients twice in order to verify reliability?
Yes, We see most of our patients for a second time as part of our protocol (pre-post testing, follow up testing), so that should be very easy to do.

8. How many of your patients are members of linguistic or ethnic minority groups?
Approximately 10% (9/50) are bilingual patients who speak English and Spanish.

9. Do you need any specific equipment support for videotaping?
Not necessarily, but it depends on which format you would prefer the data collected (e.g., tapes, DV cassettes, CDs)

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?
Yes
Again, thank you for inviting me to participate in this important research project. Please do not hesitate to contact me if I can be of further assistance as you prepare this proposal.

Sincerely,
Swathi Kiran

*******************************************************************************************
Swathi Kiran, Ph.D CCC-SLP
Assistant Professor
Rm 7.206
Department of Communication Sciences & Disorders
1 University Station, A1100
University of Texas
Austin, Texas 78712
January 12th, 2006

Drs. MacWhinney and Holland,

I want to thank you for the invitation to participate in your AphasiaBank project. I think this is very exciting and important work that has been long needed to bridge the resources in the Aphasia community. Per your request, I am providing you with responses to your 10 questions to assist in your NIH preparation. Please let me know if there is anything else I can provide.

Thank you again for taking on the coordination of this very important work.

Tracy Love, Ph.D.

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?

   For a number of years our laboratory has collected discourse samples from our participants for the purposes of behavioral classification. We are currently beginning a new set of research endeavors that will result in our expanding this collection to include chronic and 'acute' stroke survivors (3 months post onset). We have all our samples collected on audiotape.

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.
Part of our protocol dictates that we collect discourse samples from all our participants for the purposes of behavioral classification.

3. What are the goals of your current projects? Do they include specific treatment approaches?
The current research projects that are underway take two related approaches. One is a basic research program exploring the neural underpinnings of real-time sentence comprehension. The goal of the second program is to examine the brain-bases of improvements in language production and comprehension associated with language treatment and recovery of language abilities in aphasia. The areas of rehabilitation (retraining) will focus on structural disruptions to language comprehension and production in the auditory/oral modality. In addition, other main factors of interest include language changes linked to spontaneous versus treatment-based changes and a systematic comparison of the effects of intensive vs. extended (distributed) treatment schedules.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.
We use portions of the BDAE (both 2nd and 3rd editions), WAB, Boston Naming Test, Cookie Theft picture description, The Cinderella Story, the Discourse Comprehension Battery.

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?
As we currently most (if not all) of these tasks, this is not a problem for us.

6. With how many subjects could you use this suggested shared protocol each year?
We are recruiting new participants for our treatment protocol now and anticipate adding another 8-10 patients per year to our existing group. Depending on the selection criteria, this number may be modified to include more language exposed individuals.

7. Would it be possible to test some patients twice in order to verify reliability?
Absolutely. There are always some situations that make a follow up visit not possible, but for most of our participants, we see them regularly.

8. How many of your patients are members of linguistic or ethnic minority groups?
Our current protocol requires that we test monolingual English speaker, but we routinely encounter individuals who have various language backgrounds.

9. Do you need any specific equipment support for videotaping?
We would probably need to acquire a digital camera with mic input and stereo output that would allow for transfer of audio files to the computer (via memory stick or USB link).

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?
Absolutely!
Dear Drs. MacWhinney and Holland:

I am very pleased to offer my enthusiastic support of your proposal for a multimedia database of communication samples from individuals with aphasia. I think all of us who work to understand aphasia and its impact on communication struggle with the challenges of collecting data from this specialized population. Having access to a larger data base could serve the aphasia research community in so many constructive ways: To generate norms and ranges of performance of different types of discourse in aphasia, to analyze particular linguistic characteristics of aphasic language, to develop objective measures of speech fluency, etc. to name just a few. Furthermore, I see this database as an opportunity to stimulate the multi-disciplinary collaboration with different investigators coming from different perspectives that is necessary to make sense out of this exquisitely complex population. I could see countless direct applications of a database of this type to my work, and I whole-heartedly applaud your efforts and I would like to lend whatever support I can to your project.

Specifically, I am currently involved in two aphasia treatment projects: as PI on a second generation clinical trial of Constraint Induced Language Therapy (CILT) in Aphasia that is funded through the VA Rehab R & D (C3091R) and as a co-Investigator on a stroke recovery P-50 with my collaborators at UT Medical School funded through the NIH/NINDS (P01 NS046588-22 to Papanicolaou). The purpose of the VA study is to compare two intensities of use-dependent speech intervention (CILT) with an intervention that encourages all modes of communication (PACE) under intense (3 hours a day, four days a week for three weeks) versus distributed (1.5 hours a day, twice a week for 12 weeks) schedules. The NIH study aims to investigate stroke recovery using magnetoencephalography (MEG). My project on this grant is a treatment protocol in which we collect MEG imaging data on a language task pre and post CILT intervention to evaluate changes in neural function that may be associated with changes in behavior. Both of these projects include speech and language assessments pre and post treatment and at a follow-up point in time (1 month or 3 months) and would yield data that could be contributed to your database.

The assessment protocols for the two projects are the same at all time points and include the following: Western Aphasia Battery, Boston Naming Test, Action Naming Test, Cinderella retelling, BDAE Cookie Theft picture description, and natural conversation with a significant other and/or a therapist based on 1) spontaneous conversation, 2) personal pictures (provided by the subject) and 3) current topic discussion in response to study pictures of people and events (e.g. Twin Towers attack, the moon landing, John F. Kennedy). We also complete a subtest of the Apraxia Battery for Adults and hearing screening. As you see, this protocol is very similar to the protocol you are suggesting.
The only difference is the stimuli used for your “free” discourse sample, and we could easily add a Rockwell picture and additional elicitation questions to our protocol. You may want to consider adding a measure of apraxia and hearing screening to your database as well. In my next protocols I will also add a measure of short term verbal memory and attention if possible.

Between the two projects to date I have collected data on approximately 50 subjects at the first time point, and 40 of those subjects have two additional time points completed, yielding a total of 130 samples. All of the standard assessments are reviewed by a second scorer for reliability. The data are coded to de-identify the samples; the discourse samples are transcribed, and entered into electronic folders, and summaries are entered into our spreadsheet. Since the samples are de-identified, with minimal effort I believe our IRBs could be amended to allow data sharing in your database. All of the data have been collected under IRB approved protocols with informed consent. Approximately 50% of those subjects have signed informed consent to allow the sharing of video and audiotapes of their samples for research purposes. We collect our VA data using a mini digital video recorder (i.e. digital video tape) and retain the recordings of all assessment samples. We anticipate data collection will be ongoing for a minimum of six months on the VA project, and the next generation of that project is in preparation. We use a digital micro-recorder (i.e. mini-disc) and digital audio recorder for the NIH study, which are then downloaded onto our computer and saved on discs. We anticipate data collection will continue for the next three years on the NIH project, so we will be able to add a minimum of 60 additional subjects to the database in the future. If you would prefer data be collected on a digital micro-recorder and digital audio recorder, we would need a set-up at the VA to do that.

We are also collecting a subset of samples twice prior to the initiation of therapy for reliability purposes. Unfortunately, we have just begun that with the NIH protocol, so very few of the above described samples have two time-points, but we will be continuing to do that in the future. We have limited participants in our therapy research to individuals for whom English is a primary language, which makes achieving a balanced minority distribution more difficult. Currently 10% of our aphasia therapy subjects are minorities.

I would be very interested in participating in a yearly consortium meeting with other participants on this project. I believe this will be an excellent venue to foster collaborations across labs, disciplines, and geographic boundaries. I think you are both visionaries for initiating this proposal, and I look forward to your successful application.

Sincerely,

Lynn M. Maher, PhD, CCC/SLP
Research Health Science Specialist, MEDVAMC, Rehab Research
Associate Professor, Dept. of PM & R, Baylor College of Medicine
20. Milman, Lisa and Thompson, Cindy

From: l-milman@northwestern.edu
Date: January 19, 2006 9:40:44 PM GMT+01:00
To: macw@mac.com, aholland@email.arizona.edu
Cc: l-milman@northwestern.edu, ckthom@northwestern.edu
Subject: Re: invitation to join consortium
Reply-To: l-milman@northwestern.edu

Dear Audrey & Brian,

We would like to express our enthusiastic support for the development of an AphasiaBank database and also our desire to participate in the AphasiaBank consortium. As already suggested by the recent email exchange between invited participants, such a project will no doubt enhance collaborative research, lead to the expansion of current resources and tools, and accelerate our understanding of communication in aphasia.

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?
We have English and Spanish Cinderella narratives (transcription and audio recordings) from individuals with chronic aphasia (fluent and non-fluent). We also have discourse samples in which patients describe a silent Charlie Chaplin film after viewing it.

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.
We include discourse sampling for all participants in our aphasia research studies. Other formal measures include the Western Aphasia Battery, Boston Naming Test, Northwestern Assessment of Naming, and Northwestern Assessment of Verbs and Sentence Production.

3. What are the goals of your current projects? Do they include specific treatment approaches?
The primary goal of our research is to examine patterns of generalization that result from
AphasiaBank Participants

linguistically motivated language intervention. We are particularly interested in examining generalization across language forms that differ in terms of their complexity and formal structural relations.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.
We have three NIH funded projects concerned with aphasia. All participants in these studies are administered the following measures:
- Western Aphasia Battery
- Boston Naming Test
- Northwestern Naming Battery (Thompson & Weintraub, in preparation)
- Northwestern Assessment of Verbs and Sentence Production (Thompson, in preparation)
- Verb Inflection Test (Bastiaanse & Thompson, in preparation)
- Wechsler spatial and digit span tests

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?
As indicated above, we are already using many of these measures. We could also include a second picture description task (such as Cookie Theft or Norman Rockwell) and a free speech sample based on a standard set of elicitation questions.

6. With how many subjects could you use this suggested shared protocol each year?
We could use this protocol on approximately 30 participants annually.

7. Would it be possible to test some patients twice in order to verify reliability?
Yes. We routinely collect test-retest reliability data for our measures.

8. How many of your patients are members of linguistic or ethnic minority groups?
Our patient population includes the following linguistic and/or ethnic minority groups: Hispanic
(5%), Asian American (5%), and African American (5%).

9. Do you need any specific equipment support for videotaping? No, we are equipped to videotape patient sessions.

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)? Yes, we think this would provide a wonderful opportunity for collaboration.

Thank you for inviting us to participate in this very exciting project.

Sincerely,

Cynthia Thompson & Lisa Milman
Dear Drs MacWhinney and Holland,

Thank you very much for taking the initiative to finalize the grant proposal to NIH to establish, develop and share a multimedia data bank for aphasia. Unfortunately, neither of us was able to attend the workshop in May 2005, entitled “Collaborative Multimedia Analysis of Aphasic Communication”, owing to a scheduling conflict with a PhD defense.

This grant is a very important one that will add greatly to the opportunities for research collaboration and it should enhance our understanding of the complexities of aphasia in adults. We are most interested in taking part in this consortium. We are especially excited about the possibility to share data, methods of analysis, and productive dialogue and collaboration with so many researchers. In addition, the resource you are developing will be an invaluable tool for teaching. Thank you very much for inviting us to be part of this group effort. Below, we address the specific questions you asked in your recent message.

With best wishes,
Jack S. Damico, PhD
Nicole Müller
Professor
Associate Professor
Doris B. Hawthorne Eminent Scholar
Doris B. Hawthorne Endowed Professor

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data.
Jack Damico owns and could contribute approximately ten audio tapes, and approximately 15 hours of video recordings, both conversational interactions and therapy interactions.
Nicole Müller: owns and could several hours of conversations between persons with and without dementia.

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.
Jack Damico is not currently collecting data, but will do so in the future. Nicole Müller is hoping to start data collection in dementia in spring 06 (multilingual dementia). For both, the focus is on authentic conversational and therapeutic interactions. In addition, discourse samples can be collected as part of the assessment process with persons with aphasia.
3. What are the goals of your current projects? Do they include specific treatment approaches?
For Jack Damico, the focus has always been on the investigation of social interaction in conversation and in aphasia therapy sessions, rather than treatment approaches.
Nicole Müller focuses on conversational interaction between persons with and without dementia, including e.g. the use of compensatory strategies and shifting conversational responsibility in a progressive dementing condition. A new project (starting, it is hoped, in Spring of 06) will investigate language preferences and language switching in bilingual dementia.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.
No.

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?
All of the above can be included for assessment purposes. However, since our main focus is on authentic conversational interaction, genuine free conversational data (if possible with different, both familiar and unfamiliar partners) should be included. In addition, personal narratives are of great interest to us (e.g. along the lines of Labov’s ‘danger of death’ question), and narratives and / or ethnographic interviews concerning the experiences of impairment and disability of persons with aphasia and dementia, and of their caregivers.

6. With how many subjects could you use this suggested shared protocol each year?
Possibly three to five persons with aphasia per year. It is difficult to be specific concerning numbers of persons with dementia at this stage.

7. Would it be possible to test some patients twice in order to verify reliability? Yes.

8. How many of your patients are members of linguistic or ethnic minority groups?
Nicole Müller is currently working towards building up a body of bilingual participants (e.g. Louisiana French / English). Two clients with aphasia are African-Americans, one of whom speaks Louisiana French as his first language.

9. Do you need any specific equipment support for videotaping? No.

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)? Yes, very much so.
Dear Drs. MacWhinney and Holland

We are pleased to hear that you are preparing to submit an NIH grant proposal to support the development of a shared multimedia database of discourse samples obtained from individuals with aphasia. As evidenced by comparable databases that have been developed for studying other language groups (e.g. children, bilinguals), such a forum for compiling and sharing data can contribute significantly to understanding aphasia. We fully support the consortium that you propose and indicate my acceptance of the opportunity to participate via this correspondence.

I (Maria) have answered the following questions to indicate what I can contribute to the project.

1. **Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?**
   I have collected discourse samples from monolingual and bilingual (Spanish/English) individuals with aphasia. I may be unable to contribute these samples due to the IRB constraints under which the data were collected. I can investigate options regarding use of these data.

2. **Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.**
I currently have two ongoing treatment outcome research projects for which I am collecting discourse samples. Additionally, we have proposed collecting discourse samples for all evaluations conducted with individuals with aphasia. Sampling procedures include the following: WAB picnic picture, BDAE cookie theft picture, personal narratives (tell me about your stroke, tell me about your most frightening experience) and a conversation sample. For research protocols, these samples are collected pre- and post-treatment.

3. **What are the goals of your current projects? Do they include specific treatment approaches?**

I am conducting two treatment outcome studies. The first compares computer-based (Sentence Shaper) and clinician-based script training. The second examines the use of a treatment for reducing perseveration on picture naming tasks. The treatment is based on cognitive-neuropsychological explanations of the underlying cognitive-linguistic processing mechanisms that lead to perseveration.

4. **Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.**

Currently, I use the BDAE-3, BNT, TONI-3 and portions of the Wechsler Memory Scales.

5. **We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?**

I would have no problem adopting the suggested protocol. It is not substantially different from the procedures I have already implemented. Recently, I have stopped administering the WAB because it has not been updated. I am looking forward to examining the revised edition due out this year. The only additionally procedure I might suggest is some kind of working memory task. Assessing memory for individuals with aphasia is complicated by the language impairment. I have started using the Spatial Span subtest of the WMS as a general indicator of memory skill (though I realize this task captures visual rather than verbal memory span).

6. **With how many subjects could you use this suggested shared protocol each year?**

Per year, I would likely use this protocol on at least 4-6 research individuals referred for participation in a research project. If we were to adopt this protocol for use clinically, we could include 8-10 per year.

7. **Would it be possible to test some patients twice in order to verify reliability?**

Some patients, particularly those participating in research protocols could be tested twice to establish reliability.
8. **How many of your patients are members of linguistic or ethnic minority groups?**

Currently none of the patients enrolled in the research protocol or in the clinic are members of linguistic or ethnic minority groups. However, I am actively working to recruit bilingual (Spanish/English) individuals with aphasia to participate in my research projects.

9. **Do you need any specific equipment support for videotaping?**

No. I currently have two video tape recorders in my research lab. Additionally, I use a Marantz compactflash recorder to collect audio samples.

10. **Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?**

   Yes.

Dr. Karow has recently joined the faculty and is currently in the process of setting-up her research and lab but also has much to contribute. We look forward to being a participant in this project. If you have any questions or we can be of any additional service please feel free to contact Maria at 865.974.4802 or mmunoz2@utk.edu.

Sincerely,

**Maria L. Muñoz**

Maria L. Muñoz, PhD.
Assistant Professor

**Colleen Karow**

Colleen Karow, Ph.D.
Assistant Professor
Dear Brian and Audrey,

Thank you for inviting me to join the AphasiaBank consortium. This is a very exciting project, and I would be most happy to participate in any way that I can. A central bank of data from aphasia research is much needed, and your efforts to establish this resource are to be commended. As a participant in this consortium, I would provide existing data from standardized tests typically used in aphasia research (e.g., Boston Diagnostic Aphasia Examination, Western Aphasia Battery) as well as data from numerous laboratory-developed measures of language processing (e.g., discrimination of sounds, word recognition, word comprehension, word production), short-term verbal memory and learning. I can also provide samples of the Cinderella re-tell task, which is part of our standard testing protocol. Additionally, I would contribute data from these measures that will be collected in the future. All data would be “de-identified” in accordance with HIPAA regulations.

Currently, my research is supported by NIDCD grant R01 DC001924-11A2 titled “Lexical retrieval, verbal short-term memory and learning.” The overarching goal of the current project is to elucidate the cognitive organization of word processing and short-term memory and to understand the impact of these processes on learning. The theoretical model that motivates this work holds the assumption that word processing and verbal short-term memory share common processes that support access to semantic and phonological representations of words and maintenance of these same representations in verbal short-term memory. These ‘activation maintenance’ processes support completion of any language act, be it small, as in repeating a single word or more extensive, as in processing sentence material or performing a verbal span task. The research protocol for this project includes collection of data on semantic, phonological, and executive processing abilities of two sample groups, individuals with aphasia and individuals with semantic dementia. These measures are used to establish profiles of semantic, phonological, short-term memory and executive processing abilities for each participant. Composite scores for each ability are then related to measures of verbal learning and, for those individuals participating in our treatment studies, measures of treatment effects.
The aim of the protocol is to determine what aspects of language/cognitive ability are critical to learning and relearning. A specific focus within this goal is to account for our findings that semantic impairment in aphasia is particularly detrimental to learning and often impedes improvement in therapy.

Currently, I am developing a treatment protocol in collaboration with Steve Majerus (Université de Liège; Belgium) that aims to improve the ability to maintain activation of semantic and phonological representations in order to improve language function. This protocol is based on the theoretical framework described above as well as data from our studies that indicate a close relation between improvements of short-term memory and word processing abilities. An ongoing treatment-oriented project in my laboratory explores the effects of repetition priming and context (defined as relationship among words being trained) on facilitation of or interference with access to words in production. This project is carried out in collaboration with Matti Laine (Åbo Akademi University, Finland) and Ruth Fink (Moss Rehabilitation Research Institute). We first investigated short-term effects of contextual repetition priming in facilitation studies. Currently, we are investigating contextual repetition and production priming in the context of full-scale treatment studies.

With respect to the protocol that is being planned for the AphasiaBank project, I would be happy to adopt the measures you will use (WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions), most of which I already use in my research protocols. It might also be useful to include measures of verbal short-term memory and conceptual semantic knowledge (e.g., the Pyramids and Palm Trees Test or something similar). We expect to run between 25 and 30 individuals per year on our protocol and should be able to collect data on the AphasiaBank measures for most of these subjects. Additionally, it should be feasible to administer this core set of tests to some individuals twice in order to verify reliability.

With respect to the characteristics of our participants, approximately 49% are female, 51% are Male, 47% are African American, 48% Caucasian, and 5% are Asian. We anticipate that about 5% of our participants will be Hispanic.

With respect to audio or video recording equipment, my laboratory is equipped with several digital audio-recorders and a digital video-recorder. Unless you require the use of a specific version of this equipment that does not match what we currently have, we will not need additional audio and visual recording equipment. I would be most happy to attend yearly consortium meetings. Thank you once again for inviting me to participate in this most important project.

Sincerely,

Nadine Martin, Ph.D.
24. **Oelschlager, Mary**  
January 12, 2006  
Brian MacWhinney, Ph.D.  
Audrey Holland, Ph.D.  
Psychology, Carnegie Mellon University

Dear Drs. MacWhinney and Holland:

Thank you for giving me the opportunity to write a letter of support for your NIH proposal to establish a common database of multimedia materials involving persons with aphasia.

As you know, I have been in the field of clinical aphasiology for over 30 years. And, interestingly, the issues that prevailed 30 years ago still prevail. Your proposal offers a singularly creative way of addressing these very long standing issues. Despite all our study, we still do not have consensus on the nature and impact of aphasia. This is not a weakness of the field per se but representative of the difficulties arising from utilization of a diversity of research protocols and definitional stances. Your effort to establish as national databank would be a giant leap to resolve these protocol and definitional issues and put some of our longstanding questions to rest. In addition, such a databank would allow access to a population that some researchers struggle to identify due to subject limitations.

I am incredibly enthusiastic about your efforts and am numbed by the brilliance of your approach. These efforts will be recognized as a significant contribution to aphasiology specifically and the field of Speech Language Pathology generally. I heartily support your proposal and will keep my fingers crossed that it is recognized by NIH for its potential to impact all of us.

My very best,

Mary Oelschlaeger, Ph.D. Associate Professor  
Northern Arizona University, Flagstaff, Az  87011

1. **Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?**

I contributed a significant amount of my work that involves the study of natural conversation of persons with aphasia at our meeting in May. I have additional videos of other subjects that I would readily contribute to the databank.

2. **Do you or your research group have ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.**
The research protocol that my colleague, Jack Damico, and I have used has involved the video recording of natural conversations of persons with aphasia. We have also conducted interviews with spouses of aphasia as part of our study of the natural evolution of aphasia. The studies have involved following an established protocol for gathering “naturalistic” data that involves extensive videorecording and validation procedures.

3. What are the goals of your current projects? Do they include specific treatment approaches?

The goals are pretty explicit in that we are interested in how persons with aphasia succeed in conversation. This involves the identification of strategies and environmental variables that contribute to this success. We do not study treatment approaches per se.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.

Our research incorporates qualitative research design. We use standardized assessments only to provide descriptive information to readers about our subjects.

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?

As mentioned above, following collection, we use conversational analysis and thus, the above does not apply.

6. With how many subjects could you use this suggested shared protocol each year?

Again, this question does not apply to our research approach.

7. Would it be possible to test some patients twice in order to verify reliability?

8. How many of your patients are members of linguistic or ethnic minority groups?

To date, none.

9. Do you need any specific equipment support for videotaping?

No

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?

Absolutely.
25. Olness, Gloria

January 17, 2006

Brian MacWhinney, Ph.D., Carnegie Mellon University
Audrey Holland, Ph.D., University of Arizona

Dear Drs. MacWhinney and Holland:

I most enthusiastically support your proposal to NIH for development of a shared multimedia databank infrastructure for collaborative aphasia research.

As a clinical discourse linguist who has committed the next decades of my career to aphasia research, I have had a keen interest in maximizing the long-range impact and influence of my datasets, especially in light of the large investment of time and resources devoted to their design, development, and analysis. I see AphasiaBank not simply as a basis for data sharing, but more importantly, as the basis for active cross-fertilization of ideas among clinical aphasiologists who bring a wide range of expertise areas to the table. In such a multidisciplinary field, a consortium-based approach is ideal for fostering quantum advances in aphasia assessment and treatment.

My interest in contributing to a web-based aphasia databank was first realized concretely in my own NIH grant submission in April 2002, which was subsequently funded by the NIDCD (1 R03 DC005151). Included in that grant submission was a long-range goal to “develop…a database of narratives produced by African American and Caucasian adults with aphasia.” At the time, I knew of Dr. Holland’s then-current contributions to TalkBank, contacted Dr. MacWhinney regarding my desire to make my own contributions of aphasia audio discourse samples to TalkBank, and inquired about his interest in these contributions. Based on our 2002 discussions, all the data resulting from this grant to date have been transcribed in CHAT/CLAN format, and all participants have provided Informed Consent (IRB-approved) for inclusion of their audio and transcripts on TalkBank, in anticipation of eventual on-line submission.

However, it was only when I was invited by you to participate in the May 2005 “Collaborative Multimedia Analysis…” workshop that I realized this: You had conceptualized possibilities for TalkBank—now containing a subcomponent with the moniker of AphasiaBank—that far exceeded what I, or any individual, could contribute. You had the vision to bring together the individuals that would design and constitute a working consortium of research aphasiologists. I was invested in seeing this vision become a reality, and if invited to continue my involvement, fully intended to do so.

I appreciate your invitation to continue my participation in this project, and I can commit to concrete support of the project in the following ways:
1) **Existing data:** In my current study, as of December 2005, 38 individuals with mild to moderate-severe aphasia have participated or are participating in a narrative protocol. Approximately two-thirds of these individuals are Caucasians, and one-third are African Americans. An additional 3 Caucasians with aphasia and 15 African Americans with aphasia will be targeted for inclusion, plus an additional 14 individuals from each ethnic group with no aphasia.

Data are transcribed in CHAT/CLAN, or are in the process of transcription, and Informed Consent for submission of the data to TalkBank is already included in IRB procedures.

Ready for immediate submission (in addition to my extant submissions to TalkBank) are the data from 12 individuals included in an in-press publication. Additional publications in preparation include a multi-authored case study that illustrates one individual’s performance at the syntactic and discourse levels across narrative elicitation contexts. When published, it could be directly linked to the data on-line.

2) **Ongoing research protocols for collection of discourse samples:** Narratives are recorded in response to a variety of tasks and in a variety of contexts. These include picture-elicited narratives, narrative retells, narrative completion, and a wide range of spontaneous personal narratives (e.g., narratives of a frightening experience, meeting a spouse or significant other, a favorite narrative). Also recorded as part of the battery are narratives produced in a conversational context of an ethnographic questionnaire, e.g., on the topic of life milestones or turning points. Many of these include participant’s spontaneous narrations of their stroke experience.

3) **Goals of my current project:** Our ability to document functional progress in aphasia treatment is only as good as the discourse “yardsticks” we use, and one discourse type that is ubiquitous in daily life is narrative, i.e. recounting of life events.

My current data are designed and analyzed to examine some functional discourse-level measures that clinical aphasiologists might use to define the narrative production skills of groups of individuals with aphasia at different severity levels. The study also examines how these yardsticks manifest within-subjects across a wide range of narrative production contexts to find optimal clinical applications.

An additional focus is on development of ethnically sensitive and unbiased narrative measures that might be used for both African Americans and Caucasians. Representatives of both ethnic groups are included in the study. All African Americans in the current study are interviewed by an African American speech-language pathologist, and all Caucasians by a Caucasian.

In the future, I would like to apply these means of discourse sampling and analysis to within-subjects longitudinal documentation of progress during periods of aphasia therapy. Results of this research hold implications for building clinical
measures based on a broader and deeper understanding of the interactions between functional discourse, ethnicity, and aphasia.

4) **Inclusion of standardized assessments:** My ongoing NIH protocol includes administration of the Western Aphasia Battery (WAB), subsections I (Spontaneous Speech); II (Auditory Verbal Comprehension); III (Repetition); and IV (Naming), which allows for calculation of the WAB-AQ (Aphasia Quotient). Aphasia severity is also rated using the scale provided on the Boston Diagnostic Aphasia Examination.

5) **Components of the proposed shared protocol that I can adopt:** Although my current protocol cannot be significantly changed, I am on the cusp of preparing and submitting my next grant application as my current data are analyzed and published. Protocol elements agreed upon by the consortium could be easily incorporated in the new phase of research. **Additional components that I believe need to be considered:** Both monologue and dialogue (conversation) should be included, with contexts ranging from elicited to spontaneous. Elicited tasks should include not only those that result in descriptive discourse, but also those that sample other discourse genres (e.g. narrative and expository discourse). One might also consider varying the relationship between the individual with aphasia and his/her interlocutor, if feasible.

6) **Number of research participants with whom I could use this suggested protocol each year:** Over the last two and one-half years, 38 participants with aphasia have qualified for the current study and have agreed to participate. Depending on inclusion and exclusion criteria, similar numbers could be anticipated for future studies. Over 15 sites in the Dallas-Fort Worth metropolitan area have referred research participants to date, and referrals are on-going.

7) **Possibility of testing some patients twice, in order to verify reliability:** Test / re-test reliability could easily be built into a new grant submission. Also, all former participants of the current study have expressed a willingness to be contacted again should they qualify for future studies.

8) **Number of research participants who are members of linguistic or ethnic minority groups:** Both African Americans and Caucasians have been systematically included in our research to date, as noted above. Approximately 25 percent of the population in the Dallas-Fort Worth area are African Americans.

9) **Specific needs for videotape equipment support:** My research to date has been based on audio recording only. If video sampling were desired for the collaboration, I would require support for selection and purchase of video recording and processing equipment and software.

10) **Interest in being invited to participate in yearly consortium meetings:** Strong interest.
Thank you for the opportunity to submit this letter of support for your NIH grant proposal. I strongly believe that this is an important project with high probability of advancing the field of aphasiology, and I would be humbled and honored to be asked to continue my involvement. I will support the project in any way I can.

Sincerely,

Gloria Streit Olness

Gloria Streit Olness, Ph.D., CCC-SLP
Research Scientist
University of Texas at Dallas, School of Behavioral and Brain Sciences and Callier Center for Communication Disorders
Dear Dr. MacWhinney and Dr. Holland,

Thank you for inviting me to be a member of the new consortium on the Collaborative Multimedia Analysis of Aphasic Communication. I feel fortunate to have the opportunity to participate in this endeavor. I have spoken to several of the original members and am excited at the prospect of generating a large common database exploring the communication of individuals with aphasia. I believe that the only way we can heighten our understanding of the complex nature of aphasic language is through collaborative efforts and I applaud you for initiating the project.

In order to provide you with the specific information you need for your grant, I have directly answered your questions below:

1. **Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?**
   
   I do not currently have discourse data on audiotape or videotape.

2. **Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.**
   
   We collect some discourse samples during all of our initial evaluations at the clinic. Although we do not use a specific protocol at this time, we commonly use the Cookie Theft, WAB picture description, BDAE fable retelling and/or pictures from Brookshire and Nicholas’ CIU article.
3. **What are the goals of your current projects? Do they include specific treatment approaches?**
   
   Currently my research focuses on three different areas: education and training of family members of persons with aphasia, assessment and treatment of executive dysfunction in aphasia, and interdisciplinary education.

4. **Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.**
   
   Tests I use in my protocols include the WAB, CADL-2, portions of the BDAE-3, the WCST, CLQT, and portions of the D-KEFS.

5. **We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?**
   
   I could easily use your proposed protocol. Although, I routinely use the Test of Adolescent/Adult Word Finding rather than the BNT. I like that it provides information on other parts of speech as well as word finding in various contexts. I also have been using the fable retelling from the BDAE.

6. **With how many subjects could you use this suggested shared protocol each year?**
   
   We currently have approximately 30 clients with aphasia in our university clinic. We get about 10 new referrals each year. I also have access to persons in other support groups across the state.

7. **Would it be possible to test some patients twice in order to verify reliability?**
   
   Yes.

8. **How many of your patients are members of linguistic or ethnic minority groups?**
   
   Unfortunately, not many. Presently, we have 3 African Americans, 1 Hispanic, and 1 Ukrainian.

9. **Do you need any specific equipment support for videotaping?**
   
   I have access to video recording as well as digital recording.
10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?
   Definitely!

Again, I want to thank you for the invitation to participate in this important project. Please contact me if I can be of further assistance as you prepare this proposal.

Sincerely,

Mary Purdy

Mary Purdy, Ph.D., BC-ANCDS
Associate Professor
Southern Connecticut State University
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New Haven, CT 06515
(203) 392-5959
Purdym1@southernct.edu
27. Ramsberger, Gail

January 12, 2006

Brian MacWhinney, Ph.D. & Audrey Holland, Ph.D.
Carnegie Mellon University
Department of Psychology ~ Baker Hall 342c
Pittsburgh, Pennsylvania 15213

Dear Drs. MacWhinney and Holland,

We were delighted to learn of your plans to submit a proposal to NIH seeking support for the development of a system for sharing video data from persons with aphasia. We have long been envious of our colleagues who study child language and for whom the CHILDES database has been so beneficial. The prospect of having similar data available for those of us who study acquired disorders of language in adults is very exciting. We are writing this letter both to support your proposal and to express our interest in joining this new consortium.

We currently have approximately 100 VHS videotaped samples consisting of individuals with aphasia each interacting with unfamiliar interlocutors. These are semi-structured conversational dyads. The aphasic participants were shown episodes of *I Love Lucy* and then attempted to tell the story to their conversational partner. While this type of task would probably result in a monologue if the participants were non-language impaired individuals, what resulted in our study were interactions that looked very much like natural conversational interaction. We are willing to contribute these data to AphasiaBank, but anticipate it will be very difficult to obtain the necessary permissions since it has been several years since the data was collected and we may not be able to locate all of the participants. We also have a handful of videotaped samples consisting of various portions of standard aphasia assessment for which we are fairly confident that we could obtain permissions should you wish to include these in the AphasiaBank database. In addition, we have two current projects (involving approximately 10 participants) for which it would be easy to add a shared protocol if we obtained additional informed consent.

Your plan to develop a shared protocol is especially promising in our minds. Having a standardized set of data will, of course, greatly enhance the potential use of the dataset. The protocol you have suggested sounds quite adequate except that we would like to see the addition of a more natural language sample. Perhaps something similar to our data described above could be incorporated? For example, we might show a short video clip to a participant and then videotape them as they talk about the clip with a family member or friend.
Between adding the shared protocol to our ongoing and new research protocols and soliciting participants who receive services in our training clinic, we anticipate that we could contribute data from approximately fifteen participants each year with perhaps one participant per year from a linguistic or ethnic minority group. While we could budget for the additional expense of gathering data for the shared protocol in future proposals that we write, our ability to add a shared protocol to ongoing projects and with clients receiving clinical services in our training clinic would be much more feasible if there were funding to cover the expense of data collection (perhaps a student stipend).

In concluding, we offer our strongest support for this project. We look forward to being able to contribute to and utilize data stored in AphasiaBank when your proposal is funded and we are eager to participate in yearly consortium meetings.

Sincerely,

Gail Ramsberger, Sc.D., BC-ANCDS    Lise Menn, Ph.D.
Associate Professor, SLHS    Professor, Linguistics
28. Rose, Miranda

From: Miranda Rose <M.Rose@latrobe.edu.au>
Date: January 10, 2006 11:47:54 AM EST
To: Brian MacWhinney <macw@mac.com>
Subject: RE: invitation to join consortium

Dear Brian and Audrey,

Thank you so much for the invitation to support and contribute to this great idea. I am currently holidaying thru Spain, Morocco and Tanzania (not returning to work at La Trobe University until February 20th) and writing this email from an internet cafe in an ancient Roman city in Spain....please excuse spelling/punctuation errors as I am using a Spanish keyboard!! It is hard for me to write a proper letter in this situation hence I have just copied your questions here and added my responses rather than try to attach a separate letter of support.... I hope that will still be of some use to you and Audrey? I look forward to hearing the outcome of your submission. PS HAve just seen the Stealers on TV here in rural Spain with Spanish commentary!!!!!

Cheers
Miranda

Dear Brian and Audrey,

Your suggestions for an electronic data base resource is a welcome, sensible and inovative suggestion that I fully support. An enormous amoununt of research time and money could be saved with the opportunity to access high quality samples previously collected that are currently not accessible. I have several types of data that may be suitable to add to the collection and would welcome the opportunity to access other´s data in the future for upcoming projects. You requested some specific information which I have attached below:

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?

Yes. The data consists of videotaped conversational and standardised assessments of people with chronic aphasia

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.

Yes. We elicit conversational samples by engaging in a 20-minute conversation
that begins by asking an open ended question about the person’s day and progresses to questions concerning family, work life, interests, and travel opportunities.

3. What are the goals of your current projects? Do they include specific treatment approaches?

My current projects aim to measure the efficacy of particular treatments for chronic aphasia, specifically word retrieval (noun and verb) and sentence production abilities.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.

Yes. We utilise the following:

- Western Aphasia Battery (including the non-language supplemental tests e.g., Raven’s Matrices) or Boston Diagnostic Aphasia Examination
- Verb and Sentence Test
- Test of Limb and Oral Apraxia
- Apraxia Battery for Adults
- Now using Cinderalla story

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?

All

6. With how many subjects could you use this suggested shared protocol each year?

3-10. Depends on funding and numbers of research students

7. Would it be possible to test some patients twice in order to verify reliability?

We always do pre and post testing with a 4-6 months interval. It would be possible to do some multiple test re-test with small time lags.

8. How many of your patients are members of linguistic or ethnic minority groups?
None at present....we are working with monolingual English speakers primarily.

9. Do you need any specific equipment support for videotaping?

No. We videotape and then transfer onto DVD if necessary

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?

Very much so. I see this project as very needed and important and believe I have experiences and knowledge that could enhance the overall project and would welcome the chance to work collaboratively and learn from the group.

Miranda Rose, PhD
Lecturer Bachelor and Master of Speech Pathology
Problem-based Learning Coordinator
School of Human Communication Sciences
La Trobe University
Bundoora 3086
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Web:
http://www.latrobe.edu.au/hcs/hcs/staff%20profiles/rose.htm
Dear Dr. MacWhinney,

It is with the greatest of pleasure that I write this letter of agreement to participate in the AphasiaBank project. As you know, I represent a consortium of investigators at four different institutions in three states sharing a set of multicenter clinical trails of aphasia/aprosodia treatments (currently under review by NIH) and in the course of those studies we will be collecting discourse as well as standard language assessment data from participants that we would like to submit to the AphasiaBank database for archiving and sharing. There are four treatments being proposed involving a total of 240 stroke survivors participating at any one of six sites including the Houston VAMC, the Speech and Hearing Clinic at Old Dominion University in Norfolk, VA, Kessler Medical Rehabilitation Research and Education Corporation in West Orange, NJ, Brooks Rehabilitation Hospital and UF Shands at Jacksonville, FL, or the UF Health Sciences Complex (including the Brain Rehabilitation Research Center at the VAMC) in Gainesville, FL. I have attached to this letter the answers to the questions you pose regarding the nature of the data we plan to accrue as well as our interest in this collaboration.

Thanks so much for this opportunity to participate in such a worthwhile project.

Sincerely,

Leslie J Gonzalez Rothi, PhD
Career Research Scientist and Program Director, Brain Rehab Research Center, VAMC
Professor of Neurology, University of Florida
30. Sarno, Martha

From: "Sarno, Martha" <Martha.Sarno@nyumc.org>
Date: January 17, 2006 2:41:21 PM EST
To: Brian MacWhinney <macw@mac.com>
Cc: aholland@u.arizona.edu
Subject: RE: invitation to join consortium

Dear Audrey and Brian:

This is to express my support of your plan to seek NIH funding to develop a database comprised of multimedia data obtained from individuals with aphasia. The development of the described database, its byproducts, and potential access as a resource in aphasia research would help to meet a long term need. A standard set of protocols for future data collection in aphasia research is an especially appealing outcome of the plan.

Martha Taylor Sarno, MA, MD(hon)
Professor of Rehabilitation Medicine
NYU School of Medicine
Director, Speech-Language Pathology Department
Rusk Institute of Rehabilitation Medicine
400 East 34th Street RR 306
New York, N.Y. 10016

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?
   Cookie Theft audio tapes collected as part of an earlier NIH study and a foundation funded study. Contribution of the tapes would depend on IRB approval.

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.
   No current ongoing research.

3. What are the goals of your current projects? Do they include specific treatment approaches?
   No current research projects. Pending projects do not address specific treatment approaches.
4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.

Completed projects included administration of: Cookie Theft description, Visual Naming, Sentence Repetition Word Fluency, and Token Test from the NCCEA; Complex Ideational material from the BDAE; and Boston Naming Test.

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?

This would be possible if pending proposals are funded and IRB approval is obtained

6. With how many subjects could you use this suggested shared protocol each year?

Number of subjects would depend on what proposed projects are funded but in any case, no less than 20 per year.

7. Would it be possible to test some patients twice in order to verify reliability?

Probably.

8. How many of your patients are members of linguistic or ethnic minority groups?

My studies have usually limited subject selection to those for whom English is a first language or "practically native" prermorbid English fluency is verified.

9. Do you need any specific equipment support for videotaping?

Yes, a video camera and updated playback system.

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?

Yes.
31. Shadden, Barbara

From: "Barbara B. Shadden" <bshadde@uark.edu>
Date: January 8, 2006 11:07:44 AM EST
To: Brian MacWhinney <macw@mac.com>
Cc: aphasia@mail.talkbank.org
Subject: NIH support letter

January 8, 2006

Brian MacWhinney, Ph.D.
Audrey Holland, Ph.D.
Psychology
Carnegie Mellon University
Dear Drs. MacWhinney and Holland:

I am delighted to hear that you are planning to submit a proposal to NIH to support a system for sharing multimedia data from aphasic participants. The May 2005 “Collaborative Multimedia Analysis of Aphasic Communication” workshop I had the privilege to attend was truly a high point for me professionally. It was clear that the most important, productive research understandings of the nature and impact of aphasia are most likely to emerge when many researchers with multiple perspectives explore a common database of multimedia materials involving the communication of persons with aphasia. I know my research interests in renegotiating identity post-aphasia would benefit from this opportunity. I have been hoping for this invitation to participate in the consortium that you propose, and am indicating my acceptance of the opportunity through this correspondence.

I realize there are a number of questions you must address in framing the NIH research proposal. Let me provide some feedback about what I feel I can contribute through my ongoing clinical and research work here at the University of Arkansas. I am actually addressing the questions you have shared in order to be as comprehensive as possible in providing needed information.

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data? As you know, I have already contributed existing data to the existing site. I have two other data sets that have not yet been transcribed but that are on audio tape. I work with a number of clients with aphasia in our clinic, in both individual and group
treatment, as well as facilitating an ongoing stroke support group. Any and all of these contexts provide opportunities for focused data collection. 2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols. While I routinely collect a variety of discourse samples from my clients with aphasia, I am not currently using a specific research protocol for this collection. 3. What are the goals of your current projects? Do they include specific treatment approaches? Right now, my research agenda is focusing on identity issues in aphasia (both for the person with aphasia and for significant others). I am particularly exploring changes over time, and beginning the attempt to determine what factors contribute to positive adaptation to aphasia. I am not directly working with a specific treatment approach with the exception of exploring the impact of participation in an aphasia communication group. 4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using. We use portions of the BDAE (both 2nd and 3rd editions), WAB, Boston Naming Test, Cookie Theft picture description, Norman Rockwell picture descriptions, several procedural discourse tasks, and conversation. Obviously the latter are not standardized in the traditional sense although there are usable norms that suggest what normal speakers typically include or how normal speakers behave.

I have also just begun using the Linquistic Inquiry and Word Counts software (from Pennebaker’s research group) to look at changes in language output over time and with different communication partners, as well as to explore evolution of coping with aphasia in both persons with aphasia and their significant others. This is not truly standardized, but there is considerable psychometric information about the tool. 5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered? I have no problem with the proposed protocol, and would be glad to adopt this protocol for all my patients and research subjects with aphasia. I currently typically use most of these, with the exception of the Cinderella story retell task. I would lobby for use of both the Cookie Theft and Norman Rockwell pictures, since my experience is that they elicit very different types of responses. I don’t know if it is possible, but I would also love to see a conversational task that involves the person with aphasia and a
significant other. I realize the difficulty of developing such a task that would be meaningful across settings, but it would be helpful information. Perhaps a barrier task might be useful in this context.6. **With how many subjects could you use this suggested shared protocol each year?** It is difficult to tell how many new subjects could receive this assessment protocol. We probably see 10 to 15 new clients with aphasia yearly, for a variety of reasons. I also have access to two communication groups and existing clients that result in a combined total of around 12 potential subjects, with additional subjects in a stroke support group where there are both regular attendees and new attendees across any given year.7. **Would it be possible to test some patients twice in order to verify reliability?** Yes, not always, but certainly with some patients. In fact, if this project is to succeed, such testing is critical.8. **How many of your patients are members of linguistic or ethnic minority groups?** Unfortunately, very few over time, with none presently in my patient group except for one person who is Native American.9. **Do you need any specific equipment support for videotaping?**10. **Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?** Yes, absolutely, since I felt the first meeting was highly productive in every respect.

Again, I want to thank you for the invitation to participate in this important project. I truly believe that our understanding of aphasia will be profoundly improved by developing the database you both propose, and I am honored to be asked to remain involved. Please do not hesitate to contact me if I can be of further assistance as you prepare this proposal.

Sincerely,

Barbara B. Shadden

Barbara B. Shadden, Ph.D., BC-NCD
Professor and Director
Program in Communication Disorders
Co-Director, Office for Studies on Aging
University of Arkansas
Speech and Hearing Clinic
410 Arkansas Avenue
Dear Brian MacWhinney, Ph.D.
Audrey Holland, Ph.D.
Psychology
Carnegie Mellon University

I wish to express my wholehearted support for the proposal to NIH outlining a system for sharing multimedia data from aphasic participants. I was very pleased to participate in the outstanding workshop in Pittsburgh in May 2005 that focused on “Collaborative Multimedia Analysis of Aphasic Communication.” This workshop highlighted the potential for collaborative research and exploration of a common database of multimedia materials involving the communication of persons with aphasia. Through study of a common database, the field of aphasiology is most likely to make significant advances in the understanding of aphasia and successful treatment of aphasic disorders. My own research will certainly profit by a collaborative effort. My research has concentrated on discourse in aphasia and analysis of aphasia therapy sessions. Expanding my data base beyond my own video samples would markedly enhance the validity of findings and enrich conclusions. I would be thrilled to participate as a member of the consortium in order to contribute to the research of others and benefit from the data collected by fellow consortium members. Such collaborative efforts will greatly benefit the field of aphasia and ultimately the lives of individuals affected by aphasia.

Following are my responses to questions that are relevant to the NIH research proposal.

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data? I have already contributed existing data to the AphasiaBank site. In addition, I have other data sets representing group and individual aphasia therapy, as well as conversational samples of people with aphasia that would be appropriate for the AphasiaBank.

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols. Currently my data collection protocols require collection of “naturally occurring” talk of people with aphasia. Thus, people with aphasia and family members are asked to videotape identified
“events” within the daily lives of research participants. Careful discussions of confidentiality are conducted to assure ethical data collection, and video equipment is loaned to participants. In addition, we are currently collecting videotapes of aphasia therapy in order to study the discourse used by therapists and clients to manage sessions. Each therapist provides the research team with test scores (typically the Western Aphasia Battery) and a description of the client’s treatment including progress to date, goals, and demographic data. In addition, the client and family member are interviewed by a research team member to collect data on client goals, perceptions of disability, important communicative situations to the client and family, social history, and similar qualitative information to “flesh out” the individual’s communicative lifestyle.

3. What are the goals of your current projects? Do they include specific treatment approaches? My current projects are aimed at gaining a better understanding of how people with aphasia (regardless of severity) negotiate communicative situations. Qualitative research such as ethnography and conversation analysis are employed to discover common themes across individuals and/or situations. For example, one study highlighted the occurrence of various types of compensatory strategies across naturally occurring discourse settings. Such information aids significantly in devising effective and efficient therapy for people with chronic aphasia. In addition, I am interested in understanding the discourse of aphasia therapy. No specific treatment approaches have been targeted.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.
Since the purpose of my research has been to discover elements important in “natural” communication, the collected conversational samples have not been “structured”; rather the samples are “naturally” occurring interactions. However, I typically collect additional information in the form of language test(s) (e.g. WAB, PICA), picture description (e.g. cookie theft) and a structured conversational sample (e.g. standard questions).

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered? I have no problem with the proposed protocol, and would be glad to adopt this protocol for all my patients and research subjects with aphasia. In addition to the above, I would like to see a conversational sample that is not based on a standard set of elicited questions. For example, a conversation between a family member and person with aphasia often provides information about how the family has adapted to the disorder.

6. With how many subjects could you use this suggested shared protocol each year? This depends on the nature of the research in progress at any given time. We typically bring in 3 or 4 new people with aphasia into our research per year. The number of new participants are usually limited due to the depth of analysis and amount of qualitative data
collected on each. However, I work with several clinics and hospitals in the region that might be willing to share data according to this protocol, and we would adopt the protocol in our university clinic on all new admissions with aphasia.

7. *Would it be possible to test some patients twice in order to verify reliability?* Yes. we conduct reassessments routinely, and in most cases we would be able to conduct reliability retests.

8. *How many of your patients are members of linguistic or ethnic minority groups?* Approximately 50% of our research participants are African-American and 50% Caucasian.

9. *Do you need any specific equipment support for videotaping?* Not at the present time.

10. *Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?* Yes. The meeting in May 2005 was excellent. I would look forward to future meetings such as this.

Thank you very much for the invitation to participate in this important project. This project could be a “windfall” to the field of aphasia. By sharing resources and data our understanding of aphasia will be greatly enhanced. This is a wonderful project and I look forward to sharing with my colleagues. Please contact me if I can be of further assistance.

Sincerely,

*Nina Simmons-Mackie*
Professor & Scholar in Residence
Department of Communication Sciences & Disorders
Southeastern Louisiana University
Hammond, Louisiana, 70402
Dear Drs. MacWhinney and Holland,

Congratulations on your plans to submit a proposal to NIH to support a system for sharing multimedia data from aphasic participants. It was an honour and deeply rewarding to attend the May 2005 Collaborative Multimedia Analysis of Aphasic Communication workshop, and so I am very pleased to hear that this work is being expanded upon. It was clear from this meeting that the use of a common database using multimedia will be of benefit to people with aphasia, their clinicians and those who research in this area. The most exciting possibility was the promise of future international collaborations, particularly where the same text could be viewed from differing theoretical and linguistic perspectives. In addition to the database of aphasic texts, I will also be interested particularly in those from people with traumatic brain injury. I was pleased to receive this invitation to participate in the proposed consortium, and gladly accept the opportunity to be involved in the current proposal. In response to your questions, I have prepared the following responses

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data? In addition to the small amount of data I have already contributed, I have three other data sets that have been transcribed and are on video tape and/or audio tape. These texts are 1. People with traumatic brain injury interacting with friends across a number of discourse genres, and in some monologue texts; 2. People with traumatic brain injury engaged in telephone interactions with a range of communication partners and, 3. People with traumatic brain injury who have cognitive-communication deficits and dysarthria interacting on the telephone.
2. **Do you or your research group have any ongoing research protocols that collect discourse samples?** Please provide us a brief description of the protocols. I am planning a new treatment project to commence 2006 and will extend to 2008 which will involve the collection of numerous discourse samples during the course of a large multi-centre randomised controlled trial. The texts include interacting in casual conversation with a significant other for 10 minute intervals and engaging in a problem solving task.

3. **What are the goals of your current projects? Do they include specific treatment approaches?** My current projects are aimed at 1. Determining relationships between discourse measures and psychosocial outcomes; 2. Describing the discourse of people with traumatic brain injury using systemic functional linguistics and other sociolinguistic models of language and, 3. Determining treatment efficacy by working with families, carers and significant others.

4. **Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.** In the RCT to commence this year we are using the following standardised assessments: Neuropsychological: WAISIII, WMSIII, WCST, COWAT, CONNORS Continuous Performance Test, subtests of CANTAB (Delayed Matching to Sample, Rapid visual processing, Stockings of Cambridge); Social skills: The Awareness of Social Inference Test (McDonald et al., 2002).

5. **We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?** The proposed protocol appears to be entirely appropriate for studying people with aphasia. I would also strongly suggest the inclusion of a brief sample of conversational interaction, perhaps with a given purpose (such as asking the person with aphasia to give advice to others who also have aphasia). This task works well and has provided consistent responses for people with TBI (i.e., Tell me 5 things you wished you’d known just after your TBI).

6. **With how many subjects could you use this suggested shared protocol each year?** As my primary caseload is traumatic brain injury I would not be providing data for people with aphasia. However, aspects of this shared protocol could be applied to this population. I expect I could contribute approximately 10 – 20 subjects per year.

7. **Would it be possible to test some patients twice in order to verify reliability?** Yes, this should be possible.

8. **How many of your patients are members of linguistic or ethnic minority groups?** Very few of these groups qualify for inclusion in my studies.

9. **Do you need any specific equipment support for videotaping?** I’m not sure.
10. *Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?* Yes, I would be more than happy to attend such meetings following the grand success of the last one.

Thank you to you both for including me in this proposal. I wish you well in your preparations and hope for its success! It is a meritorious project which deserves funding.

Dr Leanne Togher  
School of Communication Sciences and Disorders  
University of Sydney
34. **Tucker, Karen**

**From:** "Tucker, Karen" <ktucker@adleraphasiacenter.org>
**Date:** January 11, 2006 5:01:38 PM EST
**To:** Brian MacWhinney <macw@mac.com>
**Subject:** Adler Aphasia Center

January 10, 2006

Dear Brian and Audrey

The Adler Aphasia Center is pleased to be asked to participate in the AphasiaBank consortium. Although at the present moment, we have only a minimum of ongoing research, an opportunity to participate in this consortium will be of great benefit to us, not only in terms of sharing our data, but in helping us to advance our own research agenda. As a relatively new player on the aphasia treatment scene, we feel privileged to be invited. Below please find brief answers to your questions:

1. Regarding existing data: We do not as yet have data that would be appropriate to the AphasiaBank.

2. Regarding ongoing research protocols: Similarly, at this time, we do not have research protocols to share.

3. What are the goals of the current projects? Do they include specific treatment approaches. The goals of the Adler Aphasia Center are to assist and support individuals with aphasia to get on with their lives in personally satisfying and productive ways. The Center is focused on wellness, and learning to live well with aphasia. Our approach is largely psychosocial and group participation is central.

4. Assessments currently in use: We assess our group members yearly with CADL-2 and QCL (ASHA Quality of Communicative Life Scale).

5. Additional suggested assessments: We note that you have suggested no functional measures, psychosocial or adjustment scales. It would be nice to have at least one such measure included in the protocol. Although we recognize that there are many to choose from, we would recommend A short measure such as the Burden of Stroke Scale, or QCL.

6. Subjects: We currently serve 80 aphasic participants and roughly half that number of caregivers. We would use the protocol with individuals who would volunteer to be subjects, and it is likely that at least 25 per year could be added.
to AphasiaBank from the Adler Center.

7. Testing patients twice: We estimate that we can re-test at least 20 at least twice at 6-month or yearly intervals.

8. Linguistic and ethnic minority group membership at the Adler Center: Currently, our membership would include 20% ethnic and linguistic minorities.

9. Specific equipment needs. We would need a videotape recorder and tapes.

10. Would we like to attend consortium meetings: We would plan on having at least one of our staff in attendance.

Karen Tucker
Executive Director
Adler Aphasia Center
60 West Hunter Avenue
Maywood, NJ 07607
Tel: 201-368-8585
Fax: 201-587-1909
Dear Brian,

Thank you for including me in this wonderful project. A databank for adult language samples would make a critical contribution to teaching and research in adult neurogenic communication disorders, particularly for low-incidence behavioral syndromes in which aggregate data permit analyses that would not otherwise be possible.

Here are my answers to your questions about data:

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?

At the University of Wisconsin-Madison, we have an active clinic in which language samples are routinely collected from adults with aphasia and cognitive-communication disorders. We would be happy to collaborate with you to contribute videotape samples to the AphasiaBank.

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.

We currently are collecting discourse data using the Relationship Closeness Induction Task, a series of open-ended questions that are meant to stimulate conversation between people who do not know each other well. We also routinely collect personal event narratives. Both of these are from individuals with traumatic brain injury (TBI).

3. What are the goals of your current projects? Do they include specific treatment approaches?
Ultimately, though at present the goal is to understand why adolescents and adults with TBI struggle to be successful in social conversations.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using. We use the Wechsler Memory Scales (Third Edition), Wechsler Adult Intelligence Test Vocabulary Subtest, Rivermead Behavioral Memory Test, and Kaufman Brief Intelligence Test for adults; and the Comprehensive Assessment of Spoken Language and LEITER test of nonverbal intelligence for older adolescents (the 18-21 might meet your criteria for AphasiaBank).

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered? For research participants with TBI, we could add the discourse tasks; the others might not be appropriate. For individuals with TBI, free speech samples have not adequately characterized their challenges, so a task with more of a load on executive function and working memory would be preferable. For clinic clients with aphasia, we could add the tasks listed above without difficulty.

6. With how many subjects could you use this suggested shared protocol each year? A minimum of about 10 adults with TBI, and 5 with aphasia. We also test comparison peers without injury, and could contribute those data.

7. Would it be possible to test some patients twice in order to verify reliability? Yes.

8. How many of your patients are members of linguistic or ethnic minority groups?

Not many, here in Wisconsin. Our clients and participants are primarily white men and women of Scandinavian descent.

9. Do you need any specific equipment support for videotaping? No, although it would encourage clinical videotaping if they had an additional camera.

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)? Yes, the first meeting was productive and stimulating.

Thank you again for including me in this project. Please do not hesitate to contact me if I can provide any further information.

Lyn S. Turkstra, Ph.D., CCC-SLP, BC-NCD
Assistant Professor
Dear Drs. MacWhinney and Holland,

I would like to record my support for your proposal to building up a system for sharing multimedia data from aphasic participants. Here are my responses to the questions you asked:

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data?

In principle yes, although for the data I have already collected I would have to check whether the consent forms we used would allow us to. The data consists of interactions between people with aphasia and their speech and language therapist or with an everyday conversation partner such as a spouse. It also contains test data such as naming tests, picture descriptions and elicited monologues such as the Cinderella story.

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols.

We have recently completed a 3 year research project entitled ‘Long term adaptation to conversation by people with aphasia and their partners’. This involved collecting discourse samples on videotape of naturally occurring conversations between 7 people with aphasia and their spouse over a period of around 27 months (from 3 months to 2 and a half years post onset). At each sample point we also collected interview data and also test data samples using, for example, naming tests, picture descriptions and the Cinderella story.

3. What are the goals of your current projects? Do they include specific treatment approaches?

The goals of the project described above were:

1. To investigate how people with aphasia and their main everyday conversational partner adapt to conversation with aphasia following stroke from the acute, early stages of the disorder up to two and a half years post-onset
2. To investigate the possible relationship between adaptation to conversation over this time and

   a. changes in the aphasic speaker's linguistic resources over this time
b. changes in the couple's relationship and style of relating together over this time

This project did not include specific treatment approaches, although we have carried out such projects in the past which have involved comparing discourse samples pre- and post- treatment. See e.g. Lock, S., Wilkinson, R. and Bryan, K. (2001) Supporting Partners of People with Aphasia in Relationships and Conversation (SPPARC): A Resource Pack. Bicester: Speechmark.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using.

WAB

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered?

We could adopt all of them, although I am less convinced of the use of the free speech sample based on a standard set of elicitation questions. I think an additional component to be considered would be naturally occurring interactions between people with aphasia and their speech and language therapist or (preferably) with an everyday conversation partner such as a spouse.

6. With how many subjects could you use this suggested shared protocol each year?

It would depend on future research projects since I do not currently have a clinical caseload.

7. Would it be possible to test some patients twice in order to verify reliability? In principle yes.

8. How many of your patients are members of linguistic or ethnic minority groups?

One of our inclusion criteria for our projects thus far has been that the speakers are native speakers of English, so we have few examples of data from linguistic or ethnic minority groups.

9. Do you need any specific equipment support for videotaping?

We already have the necessary equipment, at least for our current needs, although this is constantly developing.
10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)?

In principle yes although the time involved in travelling to the US may be prohibitive.

I wish you success with your proposal.

Yours sincerely,

Ray Wilkinson PhD, RCSLT
Senior Lecturer
37. Worrall, Linda

From: Linda Worrall <l.worrall@uq.edu.au>
Date: January 15, 2006 7:05:41 PM EST
To: audrey Holland <aholland@u.arizona.edu>, macw@mac.com
Subject: Letter of support - good luck with this.

Dear Drs. MacWhinney and Holland:

May I lend my wholehearted support to your proposal to NIH to support a system for sharing multimedia data from aphasic participants. I am delighted and excited that such a database may promote truly collaborative research that will advance the rehabilitation of people with aphasia throughout the world. Here are my responses to your questions:

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data? / My PhD students have videotapes, audiotapes and transcriptions of these.

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols. / My research team will be collecting digital videotaped samples that will be transcribed on 50 people with aphasia throughout Australia in the next year or two.

3. What are the goals of your current projects? Do they include specific treatment approaches? / My current projects do not involve intervention. The focus of the large scale project that will be occurring over the next few years is interviews with people with aphasia about what they want from aphasia services. I will also have interviews with their family and their treating speech pathologists.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using. / We generally use the WAB to measure the aphasic impairment.

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered? / All of these are fine. In the interviews we plan to undertake with the 50
people with aphasia, we will ask them to tell the story of their stroke.
6. With how many subjects could you use this suggested shared protocol each year?
   / 25 per year for the next 2 years. Routinely, 2 per year. /
7. Would it be possible to test some patients twice in order to verify reliability?
   / Yes, they are mostly long term clients. 
8. How many of your patients are members of linguistic or ethnic minority groups?
   / No precise figures. Probably about 5%. 
9. Do you need any specific equipment support for videotaping? No
10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)? Yes.

Sincerely,

Linda E Worrall, Ph.D. Professor and Director
Communication Disability in Ageing Research Centre
School of Health and Rehabilitation Sciences
The University of Queensland Brisbane, Queensland, 4072 Australia
38. Wright, Heather

January 17, 2006

Dear Drs. MacWhinney and Holland:

I am excited to hear about your NIH proposal to develop and support a system for sharing multimedia data collected from individuals with aphasia. Having a common database that includes language samples collected from multiple sites with a standard set of protocols is needed in the field of aphasiology. This will benefit patient-oriented treatment research in aphasia. I am excited for the opportunity to participate in the consortium proposed. My research program in discourse processing abilities of adults with and without aphasia will benefit from this opportunity. Provided below are my responses to a number of questions posted demonstrating how I can contribute through my research activities at Arizona State University.

1. Do you have any existing data that you would be willing to contribute to AphasiaBank? If so, could you please briefly describe these data? I have several datasets audiotaped and transcribed that I could contribute to the AphasiaBank. These include individuals with aphasia describing several different pictures, retelling stories from wordless picture books, and recounting life experiences (favorite vacation, recent Christmas).

2. Do you or your research group have any ongoing research protocols that collect discourse samples? Please provide us a brief description of the protocols. We are currently collecting discourse samples from individuals with aphasia describing single and sequential pictures, providing recounts, story retellings, and describing several procedures.

3. What are the goals of your current projects? Do they include specific treatment approaches? The goal of our research program is to identify changes in discourse processing in adults with aphasia compared to neurologically intact individuals and why these changes occur. We are working on developing a comprehensive and systematic description of age-related and disordered changes in discourse processing that considers the multiple components required to produce discourse. Currently, our projects do not include specific treatment approaches.

4. Do you have any ongoing research protocols that include standardized assessments? Please list the instruments you are using. We use the WAB, occasionally the Boston Naming Test, Cookie Theft picture description, Nicholas and Brooskhire’s (1993) pictures, wordless picture books – The Picnic, Good Dog Carl, several procedural discourse tasks, and several recounts.

5. We are proposing the use of a shared protocol that includes these components: WAB, Boston Naming Test, Cinderella story retell task, picture description (Cookie Theft or Norman Rockwell), and a free speech sample based on a standard set of elicitation questions. Which of these components can you adopt? What additional components do you believe need to be considered? I can easily adopt this protocol.

6. With how many subjects could you use this suggested shared protocol each year? It is difficult to estimate, however I foresee being able to collect data on 10-20 new participants with aphasia each year with the protocol.
7. Would it be possible to test some patients twice in order to verify reliability? Yes, this is not a problem at all and something that we are doing already.

8. How many of your patients are members of linguistic or ethnic minority groups? Currently, I do not have many because my line of research requires monolingual participants. However, I do have access to several bilingual (Hispanic, Spanish-English speaking) individuals who present with aphasia.

9. Do you need any specific equipment support for videotaping? I do not think so.

10. Would you be interested in being invited to participate in yearly consortium meetings (with expenses covered by the NIH grant)? Yes, absolutely!

Thank you for the invitation to participate in this project. This is a great proposal and will really benefit the field of aphasiology and the care and services we are able to provide to our clients with aphasia. Please contact me if I can be of further assistance.

Sincerely,

Heather Harris Wright, Ph.D.

Heather Harris Wright, Ph.D., CCC-SLP
Assistant Professor
Department of Speech and Hearing Sciences
Arizona State University