



**University of Illinois at Chicago
Research Information and Consent for Participation in Social Behavioral Research**

**Testing the PEM+ Online Care Planning Guide for Parents of
Young Children**

You are being asked to participate in a research study and give permission for information to be collected about your child. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Feasibility Test of a Pediatric Web-Based Care Planning Guide

Contact Principal Investigator: Mary Khetani, ScD, OTR/L, Assistant Professor

Department and Institution: Occupational Therapy, University of Illinois at Chicago

Address and Contact Information: 1919 West Taylor Street, AHSB 716-744-745, Chicago, IL 60612-7250

Sponsor: American Occupational Therapy Foundation

Why am I being asked?

You are being asked to enroll in a research study that is part of a larger project involving researchers at the University of Illinois at Chicago, in collaboration with Tufts University, McGill University, and McMaster University.

This research study is about using new online programs to quickly get information from caregivers like you on your child's current participation in activities and then guide you as a caregiver in using that information to set priorities for change and design action plans to reach your goals. The programs have been built together with parent input so that they can be used by parents just like you with busy lives and who need flexible support options.

You and your child have been asked to participate in the research because you identify as a parent or legal guardian of a young child with developmental needs. You should not enroll in this study if 1) you are under 18 years old, 2) if you do not speak, read, and write in English, 3) if your child is more than 3 years old, or 4) if you do not have internet access.

Your and your child's participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Chicago. If you and your child decide to participate, you are free to withdraw at any time without affecting that relationship.

Approximately 34 subjects may be involved in this research that is being lead by the team at UIC.

What is the purpose of this research?

Parents of young children with disabilities benefit from being a part of planning their young child's care. Parents can identify their child's needs and communicate their goals and formulate strategies to achieve their goals for their child. However, parents are often receiving services designed by professionals. Given the increasing use of technology, it may be possible for pediatric therapists and other providers to deliver some aspects of their care remotely and improve reach and parent engagement in care plan development. PEM-Plus (PEM+) is a new program that can potentially meet this need, but it needs to be tested before it is used in this way.

What procedures are involved?

This research will be performed using technology, so you don't have to travel in order to join.

Once you say 'yes' to participate in this project, you will fill out these 2 questionnaires online if you have not done so already:

1. A background questionnaire with 25 questions about you, your child, and your family.
2. The Young Children's Participation and Environment Measure (YC-PEM) home and community sections. There are 27 questions about your child's participation in activities, and your thoughts about how things in each environment impact your child's participation in activities.

Then, you will be asked to try PEM-Plus (PEM+) and also complete 8 tasks that correspond to things that a parent might need to do if they were using PEM+. For example, you might be asked to save your action plan to your computer and email it to yourself, or exit the program and log back in. After each task, you will be asked a question about task difficult. Once you finish all 8 tasks, you will answer 22 more questions about your experience with PEM+.

We think it will take 20-30 minutes to complete the questionnaires in this study (5-10 minutes to complete the family background questionnaire, 15-20 minutes to complete the YC-PEM) and 60 minutes to complete the PEM+ usability test that includes 8 tasks and a set of survey questions following task completion.

Once you have finished the usability test and satisfaction survey, you will receive a \$20.00 mailed payment.

What are the potential risks and discomforts?

You may feel uncomfortable in answering questions about your child's ability to function in everyday tasks and activities if you are not satisfied with it. You may also get tired when filling out the questionnaires and/or completing PEM+.

We have tried to lower these risks by giving you options for skipping survey questions if you are not comfortable answering them, and we will invite you to take a 2-3 minute break after each PEM+ step and each PEM+ task (8 total tasks will be given to you to complete).

There may be risks from the study that are not known at this time. To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life. A risk of this research is a loss of privacy (revealing to others that you are taking part in this study, or that you are filling out identifiable information about your child using a computer) or confidentiality (revealing information about you to others to whom you have not given permission to see this information about your child that you have submitted online).

Are there benefits to taking part in the research?

Taking part in this research study may not benefit you personally, but our research team may learn new things that will improve PEM+ for future use by therapists and other providers who work with families like your own. We often hear from parents that taking these questionnaires and doing PEM+ helps them to think about their child in new ways.

What other options are there?

You have the choice to not participate in this study. If you and your child decide to participate, you may stop participating at any time without penalty or loss of benefits. This study does not ask for your child to participate directly.

What about privacy and confidentiality?

Study information that identifies you and the consent form signed by you may be looked at and/or copied for checking up on the research by the State of Illinois auditors.

The people who will know that you are a research subject are members of the research team. Otherwise information about you will only be disclosed to others with your written permission, or if necessary to protect your rights or welfare (for example, when the UIC Office for the Protection of Research Subjects monitors the research or consent process) or if required by law.

We have set up a password-protected and linked website for you to use so that all information you give us will be kept together and confidential. We will assign you a unique identification

(ID) number when you create your user account to first enter the first study website. This ID number will be used to link your survey and PEM+ data together.

Mary Khetani and her research staff will monitor study progress and manage your payment using a password-protected website.

Once all of our information are collected in the second website, we will be given a separate file with these data, as well as a file containing study subject IDs to link both sets of data together.

The file containing IDs linked to email addresses will be stored separately in a secure location for five years, after which time they will be destroyed.

When we write about this study to share our results with you, your providers, and other researchers, you will not be identified in the materials. When we publish the results of this study, we will not include identifying information from you.

What are the costs for participating in this research?

If you and your child take part in this study, you may have to pay extra costs. These costs include internet charges to complete the first two questionnaires, testing PEM+, and completing the usability questionnaire using your personal computer.

We think it will take 80-90 minutes to complete this study. If you have not done so yet, it will take 5-10 minutes to complete the family background questionnaire and 15-20 minutes to complete the YC-PEM home and community sections. It will then take 60 minutes to complete the PEM+ test with 8 tasks and respond to questions after each task and at the end about ease of use.

Will I be reimbursed for any of my expenses or paid for my participation in this research?

If you complete the study, you will receive a total of \$20.00 and 2 reports of your child that you can share with your child's provider. You will receive your payment within approximately 30 business days by mail. You will be compensated for the entire amount, regardless of how many responses you provide in the questionnaires.

Can I withdraw or be removed from the study?

If you and your child decide to participate, you are free to withdraw your consent and discontinue participation at any time. You have the right to leave a study at any time without penalty. In the event you withdraw or are asked to leave the study, you will still be compensated as described above.

Who should I contact if I have questions?

Contact the researcher, Dr. Mary Khetani at 312-996-0942 (office) or 312-413-2850 (lab) or via email at mkhetani@uic.edu if you have any questions about this study or your part in it, and/or if you have questions, concerns or complaints about the research.

What are my rights as a research subject?

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Remember:

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Signature of Subject

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be able to send a copy of this signed and dated form to my email address.

Agreeing to take part in this study means that you will be responsible for completing up to two questionnaires about your child. Please use the boxes below to let us know your wishes regarding these options.

Do you agree to complete a demographic and YC-PEM questionnaire online about your child?

Yes No

Do you agree to complete a test of the PEM+ care planning guide online and answer questions about your experience with it?

Yes No

Do you agree to have your questionnaire data merged with your PEM+ data?

Yes No

If you said yes to the questions above, then please provide your contact information below so that someone from the research team can help you get started:

E-mail: _____ Phone: _____

Typing your name and date below represents your signature. By signing and clicking ‘submit’ you are acknowledging that you have read this information and willingly sign this consent form. After submitting, you can print this form for your records.

Signature

Date

Printed Name

Signature of Person Obtaining Consent

Date (must be same as subject's)

Printed Name of Person Obtaining Consent



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Yes No

Do you agree to have your questionnaire data merged with your PEM+ data?

Yes No

Typing your name and date below represents your signature. By signing and clicking 'submit' you are acknowledging that you have read this information and willingly sign this consent form. After submitting, you can print this form for your records.

Signature

Date

Printed Name

Signature of Person Obtaining Consent

Date (must be same as subject's)

Printed Name of Person Obtaining Consent



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1. A background questionnaire with 31 questions about you, your child, and your family.
2. The Young Children's Participation and Environment Measure (YC-PEM) that has 27 questions about your child's participation in activities, and your thoughts about how things in each environment impact participation in activities.

Then, you will complete PEM+ usability test during which you will be asked to try PEM+ for 2 weeks. Once you finish PEM+, you will answer 12 more questions about your satisfaction with PEM+.

We think it will take 20-30 minutes to complete the questionnaires in this study (5-10 minutes to complete the family background questionnaire, 15-20 minutes to complete the YC-PEM). We think it will take 30 minutes or more each week to make progress on PEM+. At the end of the 2-week period, we think it will take about 5-10 minutes to complete a short 12 item survey on your satisfaction using PEM+.

Once you have filled out both questionnaires and have engaged with PEM+ for 2 weeks, you will receive a \$40.00 mailed payment.

What are the potential risks and discomforts?

You may feel uncomfortable in answering questions about your child's ability to function in everyday tasks and activities if you are not satisfied with it. You may also get tired when filling out the questionnaires and completing PEM+. We have tried to lower these risks by giving you options for skipping questions if you are not comfortable answering them, and we will invite you to take a 2-3 minute break after the family background questionnaire and before each section of

the YC-PEM and after each PEM+ step (there are 5 steps total to complete the PEM+ process and create one action plan).

There may be risks from the study that are not known at this time. To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life. A risk of this research is a loss of privacy (revealing to others that you are taking part in this study, or that you are filling out identifiable information about your child using a computer) or confidentiality (revealing information about you to others to whom you have not given permission to see this information about your child that you have submitted online).

Are there benefits to taking part in the research?

Taking part in this research study may not benefit you personally, but we [researchers] may learn new things that will help others. We often hear from parents that taking these questionnaires helps them to think about their child's functioning in different ways.

What other options are there?

You and your child have the option to not participate in this study. If you and your child decide to participate, you may stop participating at any time without penalty or loss of benefits. This study does not ask for your child to participate directly.

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The file containing IDs linked to email addresses will be stored separately in a secure location for five years, after which time they will be destroyed. We will not be storing your summary report after taking the questionnaire, or your PEM+ care plan report.

When we write about this study to share our results with you, your providers, and other researchers, you will not be identified in the materials. When we publish the results of this study, we will not include identifying information from you.

What are the costs for participating in this research?

If you and your child take part in this study, you may have to pay extra costs. The only costs you and your child may have from this study are internet charges to complete the first two questionnaires using your personal computer. We think it will take 20-30 minutes to complete the questionnaires in this study (5-10 minutes to complete the family background questionnaire, 15-20 minutes to complete the YC-PEM). Parents who have tried PEM+ have been able to develop care plans in 30-60 minutes. We think that parents will spend 30 minutes or more each of 2 weeks to make progress while engaged with PEM+.

Will I be reimbursed for any of my expenses or paid for my participation in this research?

If you complete the study, you will receive a total of \$40.00. You will receive your payment within approximately 30 business days by mail. You will be compensated for half of this amount, if you complete less than 1 week of the program. You will be compensated for the full amount if you complete 2 weeks of the program.

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