


Translation of the Involvement Matrix tool into Brazilian Portuguese


Tradução da ferramenta Involvement Matrix para o português brasileiro


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Abstract

Introduction: Patient and public involvement has numerous benefits for research; however, there are challenges to its implementation, such as the lack of tools to guide participant engagement in research. The Involvement Matrix (IM) is a tool that facilitates discussion about the role that participants play in research projects, promoting more active public involvement. **Objective:** To translate IM materials into Brazilian Portuguese in order to facilitate their use and guide researchers. **Methods:** Authorization to translate the original material into Brazilian Portuguese was obtained from the authors. Next, the translated material underwent backtranslation. The resulting version was verified by the original IM authors, ensuring semantic and content accuracy. **Results:** The Involvement Matrix (IM) was translated into Portuguese and then backtranslated into English. The researchers discussed the translated version with the IM authors, with minimal adjustments needed in the backtranslation, and no changes made to the Portuguese version. After the approval of the final Brazilian Portuguese version, the translated tools were made available, including a Practical Guide, a Word Version, a Checklist, a Fact Sheet, an Overview with Examples, and an Animated Video with Brazilian Portuguese subtitles. **Conclusion:** The various IM materials are adequately translated and freely available for use in Brazil. It is a valuable tool to guide public and patient involvement in research.

Keywords: Public Involvement. Translation. Youth.

Resumo

Introdução: O envolvimento do paciente e do público traz diversos benefícios para a pesquisa, no entanto, existem desafios para sua implementação, como a falta de ferramentas que orientem o engajamento dos participantes em pesquisas que os envolvem. A *Involvement Matrix (IM)* é uma ferramenta que facilita o diálogo sobre o papel que o participante da pesquisa deseja desempenhar em projetos de pesquisas promovendo um envolvimento mais ativo desse público. **Objetivo:** Traduzir os materiais da IM para o português brasileiro, a fim de disponibilizar seu uso no Brasil e orientar pesquisadores. **Métodos:** Solicitou-se autorização aos autores do instrumento original para traduzi-lo para o português brasileiro. Em seguida, o material traduzido passou por um processo de retrotradução. O resultado foi verificado pelos autores da IM, garantindo a precisão semântica e de conteúdo. **Resultados:** A Matriz de Envolvimento (ME) foi traduzida para o português e retrotraduzida ao inglês. Posteriormente, os pesquisadores da versão brasileira realizaram uma reunião com os autores da ME para esclarecer dúvidas, havendo a necessidade de mínimos ajustes na retrotradução, sem mudanças da versão em português. Após a aprovação da versão final em português brasileiro, foram disponibilizadas as ferramentas traduzidas: um Guia Prático, uma Versão em Word, uma Lista de Verificação, uma Ficha Técnica, uma Visão Geral com Exemplos e um Vídeo Animado legendado em português brasileiro. **Conclusão:** Os diversos materiais da ME estão adequadamente traduzidos e disponíveis gratuitamente para uso no Brasil. Trata-se de uma ferramenta valiosa para guiar o envolvimento do público e do paciente em pesquisas.

Palavras-chaves: Participação do público. Tradução. Jovem.

Introduction

Patient and public involvement (PPI) is defined as research conducted “with” or “by” members of the public instead of “for” or “about” them.¹ PPI favors participant empowerment, especially those that commonly have no voice. It has been increasingly used in high-income countries² and should be encouraged in Brazil, aimed at changing a common reality, where the social needs of children and adolescents with disabilities are often ignored and who may receive insufficient therapeutic care.³

In addition, PPI is associated with ratification of the United Nations Convention on the Rights of the Child,⁴ which states that all children have the right to be heard regarding issues that affect them, without discrimination and regardless of their disabilities. The benefits of PPI include prioritizing research that is relevant and important for patients and the public; identifying problems and details that researchers may not be aware of (for example, a focus on results that are important for study participants); study protocols and interventions that are more acceptable and sustainable; recruitment and publicity materials that are more age-appropriate and accessible; and more far-reaching dissemination of study results.^{5,6}

Van Scheven et al.⁷ reported that young people with chronic health conditions have always played a passive role in health projects and social assistance, as research and intervention subjects, and instrument users, and that there is a growing consensus they should be actively involved in issues pertinent to them. Involving children and adolescents with disability in research is essential because they are in an ideal position to say what works and which measures may be more effective for them and their families. With respect to adolescents with chronic health conditions, researchers argue that PPI improves the relevance and quality of projects and contributes to their personal development.^{5,8}

In the current context, most studies still do not use tools or resources specifically developed to involve patients and the target population and fail to include them in the research process, considering only the decisions of the researchers themselves. Another challenge is to maintain enthusiasm in all the phases of a project, given that engagement levels may decline during the process, primarily due to subjects’ disappointment with their participation. In order to address these barriers, new and more efficient forms of involvement should be devised.^{5,9} In this respect, the *Involvement Matrix (IM)* is a tool that helps patients determine the role they want to play in a project/study and was developed to promote collaboration with patients from the age of 12 years onwards. The IM was created in conjunction with researchers and patients between January 2017 and December 2018 and applied in Holland by three main institutions: the Utrecht Center for Rehabilitation Medicine (research center), BOSK (patient association) and Stichting OuderInzicht (foundation to support parent involvement in research).^{10,11}

Given the importance of the IM in PPI and its relevance for research in Brazil, this tool is an important ally in Brazilian research. To date, however, these materials have not been translated into Brazilian Portuguese, thereby hampering their use in the country. Translating the IM may encourage the adoption of PPI in studies involving young people, guiding researchers and patients. Thus, the aim of the present study was to translate the IM materials to Brazilian Portuguese.

Methods

This methodological study to translate English into Brazilian Portuguese is part of a project approved by the Ethics Committee of the Trairi School of Health Sciences, Federal University of Rio Grande do Norte (CAEE: 51319321.1.0000.5568).

IM tool

IM focuses on the roles that a patient/individual may play and the practical execution phases of a project. The different involvement roles function horizontally. The phases of the project are arranged vertically. The combination of roles and phases result in a matrix with several cells. The IM¹⁰ contains five roles of involvement for patients/the public:

- 1) The listener has a less active role, but is certainly not less important in the project.
- 2) The co-thinker can ask questions and give feedback and opinions.
- 3) The advisor requires feedback from project leaders to patients on whether the advice was followed or not.
- 4) The partner is valuable not only at the onset of a project, but also during the intermediate phases.
- 5) The decision maker requires project leaders to have a more passive attitude (let others make decisions).

The project leader, who is commonly the principal investigator, uses the IM as a guide to dialog with patients/the public. The tool can also help focus more on collaboration; improve it; and report on it more systematically.¹⁰

With a view to promoting and facilitating IM application, the team in charge of the tool produced different materials on how to use it:

Practical Guide: 5-page guide to use the matrix, containing guidance and explanations on the roles and

phases during the project, how to use the matrix as a dialog tool, recommendations for project leaders, hints and tricks to use the tool and an image of the matrix explaining how to fill it out.

Word-version: One-page Word version of the IM with empty cells, allowing it to be edited and filled out on a computer during the research phases.

Checklist: Two-page checklist aimed at guiding researchers on the stages that should be followed and that can be filled out as the project progresses. The pages contain spaces to describe what was done, depending on the current stage.

Factsheet: Two-page technical document that summarizes the materials available to use the IM and the main concepts that govern the tool.

Overview with examples: Overview of the IM containing examples of how to fill it out. The one-page document contains an image of a completed IM, with fictitious examples for researchers to use as a reference during their research project.

Animated film: Animated 2 minute and 35 second film, presenting the IM's fundamental concepts.

Procedures

Translation of the tool involved a physiotherapy doctoral student and two physiotherapy professors, native speakers of the target language and fluent in English, as well as a Master's student in rehabilitation sciences. Initially, authorization to translate the IM into Brazilian Portuguese was obtained from the original authors. A native Brazilian Portuguese speaker fluent in English translated the document. Next, the translated material was backtranslated and if needed, new changes were made, translated into English by a specialist fluent in both languages with no previous knowledge of the original English version. The backtranslation was sent to the team in charge of IM construction for a detailed verification of semantics and content by the authors and if needed, new changes were made, returning to backtranslation and author verification (Figure 1).

Results

The IM developers called for a meeting to clarify backtranslation doubts and provide suggestions for changes in some expressions. After this process, the final

version in Brazilian Portuguese was approved and the materials translated were subsequently made available free of charge on the official website.

The titles of the translated materials were: Involvement Matrix (Figure 2), Practical Guide (Figure 3), Checklist (Figure 4), Factsheet, an overview with examples (Figure 5), and an animated video subtitled in Brazilian Portuguese entitled *Involvement matrix subtitled Portuguese*.¹² The versions translated into Brazilian Portuguese can be found on the web page of the tool, along with Dutch, English and Spanish versions.¹⁰

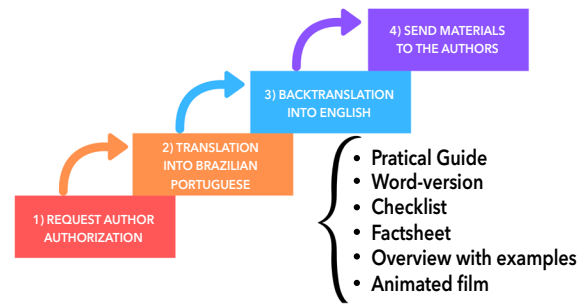


Figure 1 - Involvement Matrix translation stages from English to Brazilian Portuguese.

Uma explicação dos cinco papéis pode ser encontrada na próxima página
Por favor leia o guia prático antes de usar a Matriz de Envolvimento

		PAPEL NO PROJETO/PESQUISA				
		Ouvinte <i>Recebe a informação</i>	Co-pensador <i>É convidado a dar opinião</i>	Consultor <i>Dá conselhos não solicitados</i>	Parceiro <i>Trabalha como um parceiro igual</i>	Tomador de decisão <i>Toma a iniciativa, decisão (final)</i>
Fases do projeto/pesquisa	Preparação					
	Execução					
	Implementação					

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Figure 2 - Word version translated into Brazilian Portuguese.

Discussion

The aim of the present study was to translate the IM and its support tools into Brazilian Portuguese. This translation has numerous benefits, such as the possibility of using these materials in Brazil, expanding access to IM tools. Thus, dissemination of the PPI concept is promoted among professionals, family members and Brazilian researchers, facilitating its application in clinical, educational and research settings. In addition, the IM encourages and supports active patient/public participation in studies involving them. This leads to greater inclusion and empowerment of these participants, thereby contributing to research being

more relevant, coherent and aligned with their needs and experiences.

The IM has been used by many researchers, and there is already a Spanish version named *Matriz de participación*.¹³ Van Schelven et al.,¹⁴ used the tool to investigate the involvement of young people with chronic diseases who participated in research projects. At the end of the projects, the teams were asked to fill out the IM, describing public and patient involvement and recording them in the corresponding cells. This approach provides a data source to obtain information on the perspective of these individuals about their involvement in research projects aimed at promoting their inclusion in society.

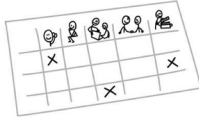
Matriz de Envolvimento

Envolvimento de pacientes em projetos e pesquisas

Guia Prático

Março 2019

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Desenvolvido pelo Centro de Excelência para Medicina de Reabilitação de Utrecht, em colaboração com a BOSK e especialistas por experiência própria; jovens e pais
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Matriz de Envolvimento - Lista de verificação para líderes de projeto/pesquisadores

Karen van Meeteren

Ao usar a Matriz de Envolvimento em um diálogo durante a interação de um projeto com um paciente/especialista por experiência, é útil realizar uma série de etapas. A lista de verificação a seguir fornece essas etapas, que podem ser completadas conforme você avança. A lista de verificação pode ser preenchida na ordem que você quiser.

Antes do diálogo

- Leia a Matriz de Envolvimento e seu Guia Prático que a acompanha.
- Familiarize-se com os cinco diferentes papéis dos pacientes.
- Faça uma lista de fases e subfases específicas e atividades potenciais do projeto.¹
- Imprima a Matriz de Envolvimento para que você possa visualizar todas as opções de envolvimento.
- Tenha uma cópia digital da Matriz de Envolvimento ou do formulário impresso em mãos para que você possa registrar os acordos que fizer durante o diálogo.

Durante o diálogo

- Apresente o projeto ao paciente.
- Apresente os vários papéis ao paciente e verifique se o paciente compreende.
- Faça uma série de importantes perguntas abertas ao paciente, tais como:
 - o Quais são seus pontos fortes?
 - o O que você gostaria de fazer neste projeto?
 - o O que você seria capaz de fazer neste projeto?
 - o Com que antecedência você deseja planejar suas atividades?
- Trabalhe progressivamente na lista de fases e subfases específicas e possíveis atividades do projeto em conjunto.²
- Faça acordos definitivos sobre atividades reais para cada fase do projeto e registre-as no formulário.
- Planeje uma data para uma próxima discussão presencial cujos objetivos serão 1) avaliar a interação até o momento, 2) tomar providências adicionais para as próximas atividades e fases.
- Organize como você manterá contato entre as duas reuniões presenciais. Decida os meios pelos quais você se comunicará e com que frequência.

Figure 3 - Illustration of a section of the Practical Guide translated into Brazilian Portuguese.

Figure 4 - Illustration of a section of the Checklist translated into Brazilian Portuguese.

Fase/Papel	Ouvinte	Co-pensador	Conselheiro	Parceiro	Tomador de decisão
Preparação	Jovens são informados sobre uma ferramenta de comunicação (WhatsApp) do projeto	Jovens são convidados a testar um questionário online	Jovens fornecem comentários sobre uma carta de recrutamento para os participantes recrutados	Jovens contribuem na redação de um artigo sobre o objetivo do projeto, que será publicado na revista da associação de pacientes	Jovens criam uma página no Facebook para aumentar a visibilidade do projeto
Execução	Jovens estão presentes durante a reunião do projeto	Jovens são questionados sobre ideias para perguntas de entrevista que serão feitas aos participantes	Jovens fornecem contribuições para um pôster que será apresentado pelo líder do projeto em um congresso	Jovens e o pesquisador analisam fragmentos de entrevistas juntos	Jovens preparam uma apresentação e a apresentam em um congresso internacional
Implementação	Jovens recebem um boletim informativo sobre o projeto	Jovens leem uma versão preliminar de um infográfico e dão sugestões	Jovens são questionados sobre a priorização da implementação de produtos	Jovens participam de uma campanha promocional para a divulgação dos resultados do projeto	Jovens criam e mantêm uma página da web destinada a colegas com a mesma deficiência que eles

Figure 5 - Overview with examples translated into Brazilian Portuguese.

In another study conducted by Pozniak et al.,¹⁵ the parents of children with development disorder were invited to participate in the development and implementation of health guidance workshops. In this respect, the IM made it possible to map the activities of all the parents involved in the research program, providing information on the level of involvement of each one throughout the study.

Dada et al.,¹⁶ reported that the IM aimed to help plan the involvement of young people with severe communication disabilities in the research project, in addition to mapping project activities. The matrix was also used to support this involvement, considering participant interest, their availability and consent to be involved.

The absence of tools that facilitate public involvement in Brazilian research may explain the lack of studies where adolescents with severe disabilities are co-researchers and/or active participants in some stage. A recently published protocol proposes using the IM to guide the construction of an intervention to promote participation in leisure activities by adolescents with cerebral palsy at GMFCS levels IV and V in Brazil and Spain, in partnership with the adolescents, their families and health professionals.¹⁷

Given the lack of tools available in Brazil to facilitate target population engagement in research, the availability of these materials in Brazilian Portuguese is beneficial to professionals, researchers, patients and families. This initiative may promote greater involvement of all the parties involved, producing partnerships and strengthening the quality and impact of interventions and research on the fields of health and rehabilitation.

Conclusion

The Involvement Matrix was translated into Brazilian Portuguese, with the name Matriz de Envolvimento. IM materials are available in Brazil and researchers should encourage their use globally. The free availability of the tool facilitates its use in all Brazilian scenarios, where research resources are often limited. Its easy application, with tools and practical guides, also contributes its accessibility and applicability. As such, the IM stands out as an accessible and practical tool that is driving quality research in PPI in Brazil.

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Authors' contributions

CCAFJ conceived the study and analyzed the data. ACC, CASS and EL conceived the manuscript and with BHB, KSM and CCAFJ, wrote it. All the authors revised the final version of the manuscript.

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