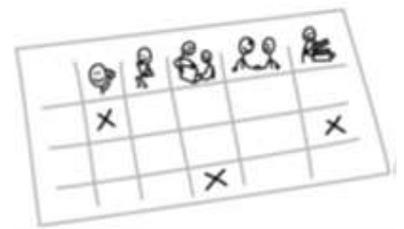


The Involvement Matrix: Nothing about us without us



Dirk-Wouter Smits, Marjolijn Ketelaar (Center of Excellence for Rehabilitation Medicine Utrecht), Karen van Meeteren, Marjolein Kloet (OuderInzicht), Rebecca ter Mors, Lauren Sluiter (FNO youth panel), Johannes Verheijden (BOSK) and Femke van Schelven (Nivel, Netherlands Institute for Health Services Research)

Background

Experience experts* are people whose own experiences have equipped them to become experts in a certain area. These could be people with a handicap or illness or their family or friends, for example. However, it is often the case that they have no input into projects and research which are aimed at improving care. Projects just pass them by and their voices go unheard throughout the process. Input from experience experts is not automatically included in projects and so for this reason, in collaboration with a group of experience experts, a tool to promote their input into projects has been developed.

The tool

The tool is known as the **Involvement Matrix**. It is a resource for project leaders and researchers. Using this resource enables them to enter into dialogue with experience experts about the various roles that experience experts can play at each phase of a project. Based on a literature search and the views of expert panels, five roles of involvement have been incorporated into the Involvement Matrix: the *Listener*, the *Co-thinker*, the *Advisor*, the *Partner* and the *Decision-maker*.



Listener



Co-thinker



Advisor



Partner



Decision-maker

Associated products

We have developed a number of products to help to use the Involvement Matrix:

- The Involvement Matrix with a **brief explanation** on the second page
- A digital **form version** of the Involvement Matrix that can be filled in
- An **animated film** about the ideas behind the Involvement Matrix
- A **practical guide** focused on the practical use of the Involvement Matrix as a resource to promote dialogue
- A **checklist** for using the Involvement Matrix
- An overview with **examples** from an existing project illustrating how the roles are filled by phase

Some examples of input from experience experts

Listener	Co-thinker	Advisor	Partner	Decision-maker
- Access to a request for a subsidy	- Giving an opinion about an idea for a project	- Input into a recruitment letter	- Co-analysis of interview data	- Giving a conference presentation
- Being present at a project meeting	- Trying out a questionnaire	- Recommending topics for interviews	- Co-writing an article, e.g. for a patients' association magazine	- Building and maintaining a website for patients/experience experts
- Receiving a clear and understandable version of the results	- Brainstorming on dissemination of project results	- Giving advice on a post-project follow-up plan		

* 'Experience experts' can be broadly interpreted here (people with a disability, young people, parents, relatives, etc.)

Lessons learned

First impressions of users of the Involvement Matrix

“This is a marvellous instrument that finally gives peer advisors the credit they deserve”

“Working with the Involvement Matrix always means real contact with the patient”

“It ensures that we don’t talk about patients but talk with them”

Insights obtained during the development and implementation of the Involvement Matrix

Input from experience experts into research and other projects has proved to be a highly topical item. The Involvement Matrix can now give concrete form to this. First impressions show that users are finding it a very promising instrument. Its additional value is that researchers, project leaders and experience experts are able to make clearly defined agreements about the nature of their involvement at various phases of a project. However, we did learn that promoting patient involvement is not simple. A project requires the following: 1) clear and meaningful goals; 2) time and remuneration; and 3) flexibility and openness. These requirements resulted from an evaluation by the Netherlands Institute for Health Services Research (Nivel) and the Center of Excellence for Rehabilitation Medicine Utrecht under the auspices of the FNO programme ‘Zorg én Perspectief’ in which 15 projects shared their experiences with the Involvement Matrix with us.

A collective challenge

The greater aim of working in collaboration with experience experts is to enable the project to have a larger societal impact. The Involvement Matrix is just one instrument for doing this. Work on other, adjunct initiatives and instruments is currently ongoing (see www.participatiekompas.nl). In view of these emerging initiatives, it is advisable for researchers and project leaders to become acquainted with training to work with experience experts. However, currently there are very few training courses in this area. The development of training courses is highly recommended, once again with, and by, experience experts. Follow-up, ‘on the job’ guidance is also recommended. In addition, there are the so-called key stakeholders who are willing to share their experiences.

A few sources of information and ‘food for inspiration’

Websites with information on working with experience experts on projects and research:

- International
 - www.invo.org.uk
 - www.pcori.org
 - www.pencru.org
- Dutch:
 - www.participatiematrix.nl
 - www.participatiekompas.nl
 - www.zonmw.nl/uploads/tx_vipublicaties/Een_10_voor_patientenparticipatie.pdf