The Involvement Matrix
Involvement of patients
in projects and research

Practical Guide

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Vereniging van mensen met een lichamelijke handicap

Developed by the Center of Excellence for Rehabilitation Medicine Utrecht, in collaboration with the BOSK and with experience experts; youths and parents

INTRODUCTION

The Involvement Matrix has been developed to promote collaboration with patients[*] (from the age of 12) in projects and research. It is a tool for project leaders/researchers. This tool is an aid to dialogue with the patient about the role the patient wishes to play in a project.

This will support project leaders to 1) focus more on collaboration; 2) improve (organisation of) collaboration; and 3) to report on collaboration more systematically.

The use of the Involvement Matrix in dialogues will ultimately lead to patients having influence in the project in a way that is appropriate to them. As a project leader and a patient enter into dialogue together, they will know what to expect from each other, they will work better together and more benefit will be derived from collaboration. This will be instrumental in making projects more relevant with a greater impact.

The creation of the Involvement Matrix was based on a literature study and various panels of experts. The origin of the Involvement Matrix lies in Arnstein's ladder of participation.[**] However, unlike the original participation ladder, in the Involvement Matrix we do not speak of 'levels' (i.e. a vertical, hierarchical approach) but of 'roles' (i.e. a horizontal, equal approach).[†]
This is also conveyed in the appearance of the Matrix: the roles are presented horizontally.

The Involvement Matrix includes only those roles that represent collaboration on a project. For this reason, the role of study subject (i.e. respondent) and 'decorative' roles (i.e. present but with no understanding of a project)[‡] are not part of the Matrix.

A key element of the Matrix is that it links the roles of collaboration to phases of projects.

This practical guide is a concise guide for project leaders. Consecutively, it covers:
- the 'what': roles, phases and activities of a project
- and the 'how': principles of having dialogues and concrete recommendations for using the Matrix

WHAT? ROLES, PHASES AND ACTIVITIES

At the core of the Involvement Matrix lie the **roles** and the **phases** of a project.

The diverse involvement roles run horizontally. The diverse project phases run vertically.
The combining of roles and phases results in a 'Matrix' with a number of cells.
After all, patients may wish to fulfil different roles at different phases.

Involvement roles
The Involvement Matrix distinguishes five involvement roles for patients. On page 2 of the Involvement Matrix, these five roles are defined and examples are given.

Listener   Co-thinker   Advisor   Partner   Decision-maker

When using the Involvement Matrix, project leaders should be aware that the role of:
- *Listener* is a less active role but certainly not less important in the project
- *Co-thinker* can also involve asking questions and giving feedback, as well as giving an opinion
- *Advisor* requires feedback from project leaders to patients on whether or not advice has been followed
- *Partner* is valuable not only at the start of a project but also at the intermediate and final phases
- *Decision-maker* requires project leaders to have a 'hands off' attitude

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[*] 'Patients' can be broadly interpreted here (experience experts; people with a disability, young people, parents, relatives, etc.)
[**] Arnstein (1969). A ladder of citizen participation. Journal of the American Institute of Planners, 35(4), 216-224
[†] Smit et al. (2011). Fundamenteel onderzoek en patiëntenorganisaties: een verrassende combinatie. Badhoevedorp: De Adelaar
[‡] Dedding et al. (2013). Kinderen en jongeren actief in wetenschappelijk onderzoek. Tielt: Uitgeverij Lannoo N.V.

Project phases

The Involvement Matrix introduces three main phases of a project. There is space to add more phases and sub-phases. Users can adapt this to their own projects themselves. It is strongly recommended that the phases are described <u>as concisely as possible</u>; this makes filling in the cells easier and more meaningful.

Examples of sub-phases within the proposed main phases are:
- in the *preparation phase*: e.g. developing ideas, formulating questions, financing, ethical approval
- in the *execution phase*: e.g. recruiting study subjects, choosing instruments, data collection, data analysis
- in the *implementation phase*: e.g. report writing, dissemination in the media, translation to practice

Filling in the cells

The project leader uses the Matrix as a guide to having dialogues with patients. Agreements are made about *the role* the patient wishes to (and is able to) play during *which phase*. In this manner, the empty cells in the Matrix fill up with specific activities for a patient in a project.

HOW? OPEN DIALOGUES

The <u>dialogue</u>s in which the Involvement Matrix is used are <u>open dialogues</u>; their structure and content are not determined beforehand. After a brief introduction, one of the first questions a project leader could ask is "Can you tell me how you picture your role in this project/phase?"

It is essential that the project leader asks open questions and is not judgemental, so the patient is able to freely express their own ideas and wishes. The project leader is responsible for initiating the <u>dialogue</u>. Preferably 1-to-1 and face-to-face with the patient doing most of the talking. In this way, every patient can express their *individual* involvement (something that is often more difficult in a group setting).
The project leader must listen very carefully and ask further questions, while also paying attention to the various roles in the Involvement Matrix linked to one or more phases of the project.

There is also an option to introduce the open dialogues in an interactive way. The atmosphere of the project, the patient's preferences and the style of the project leader all determine this choice. Examples are card games, board games, games played on the floor and a game played with caps, it doesn't matter how, as long as the five roles are still kept in the picture and linked to the phases of the project.

USING THE INVOLVEMENT MATRIX AS A DIALOGUE TOOL

As a means of <u>dialogue</u>, the Involvement Matrix can be used both prospectively and retrospectively. In this practical guide we describe how the Involvement Matrix is used prospectively (i.e. making agreements), and complemental to that, how it can be used retrospectively (i.e. at an intermediate and final evaluation).

The first step in a new project is to have an open dialogue using the Involvement Matrix as a frame of reference. It is important to describe the phases/sub-phases associated with the project as clearly as possible, but with the understanding that things may well change. Subsequently, one or more roles (listener, co-thinker, advisor, partner, decision-maker) are provisionally linked to one or more phases/sub-phases. The agreements are then translated into practical activities for the patient within the project. This specifying of activities does not immediately need to be as complete as possible for the entire project; it can also be a step-by-step process (e.g. one activity per phase or sub-phase).

A good way of doing this is, after the phases have been described and the potential roles are understood, that both patient and project leader should fill in the details of 'which role at which phase'. Then they can compare *their points of view* and discuss them further. This way of working promotes a deeper understanding of each other's perspective. Finally, consensus on a conclusion will be reached and the outcomes (agreements concerning activities) can be recorded. These outcomes are not fixed and can be updated as necessary, e.g. at each new phase/sub-phase of the project.

In this way, time to look towards the future will be created (and also time to look back). This point in time is known as an 'intersection'. At one of these intersections, the patient and the project leader can evaluate the roles and specific activities together.

Examples can be found on the last page of this practical guide. In order to facilitate the use of the Involvement Matrix as a dialogue tool, a *digital form to use the Matrix,* a *checklist* and an *overview with examples* are available.

RECOMMENDATIONS FOR PROJECT LEADERS

- As project leader, also reach out to patient groups and stakeholder groups for collaboration on the project, as well as to individual patients
- As project leader, take the first step to initiate <u>dialogues</u> with the patients about the desired roles
- In doing this, explicitly emphasise to patients that they are the experts and that their ideas cannot be wrong
- Plan regular <u>dialogue</u> sessions to fill in the Matrix (e.g. once every 2 - 3 months, and certainly at every new phase of the project), and include these in the programme planning
- Show the Involvement Matrix at every <u>dialogue</u> session (thus making it concrete)
- Describe the phases/sub-phases in advance, before the <u>dialogue</u> sessions, and make them as specific and concrete as possible
- At every phase/sub-phase look forwards as well as backwards at the roles and activities you have decided upon
- You should both be aware that 'no collaborative role' is also an option that can be introduced at various phases/sub-phases, even though this is not in the Involvement Matrix itself
- Do not make agreements about roles and specific activities too far in advance and not necessarily for several phases at the same time (this is often too complex), but limit agreements to the next phase/sub-phase

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***Tips & tricks for using the Involvement Matrix with patients***

- **Tell the patients at an early stage** that you want to discuss about the role the patient wishes to play in the project
- Possibly, consider an **interactive way** (possibly using a game) of introducing the dialogues; this interactive introduction can be done in a group, although the open dialogues should preferably be carried out on a 1-to-1 basis
- Carry out the dialogues on roles in **safe and pleasant surroundings** (e.g. at home or in a café).
- Consider **remuneration** (e.g. in the form of money/vouchers/study credits), whereby the value of the remuneration differs per role ('decision-maker' normally requires more time and effort that 'listener')
- Realise that this approach requires **time and flexibility**, due particularly to intensive and regular communication; ultimately it will result in a project that is more relevant and has greater impact!

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Example 1: Filling in the Involvement Matrix (here: *looking forward*)

Step-by-step:

1. Introduce and describe the **phases/sub-phases** that will shortly be discussed In the *example* below the focus is on the preparation phase, with the specific sub-phase: 'Compile an ethically responsible recruitment letter for future respondents in research'

2. Discuss the various **involvement roles** within the specific phase and make a choice In this *example*, the role of 'Advisor' was chosen by both parties

3. Together, formulate the **specific activity/activities** belonging to the role in the concerning phase/sub-phase In this example, the activity of the patient (in the cell "Recruitment letter + Advisor") will be formulated as: 'Give advice on the writing of the recruitment letter for respondents'
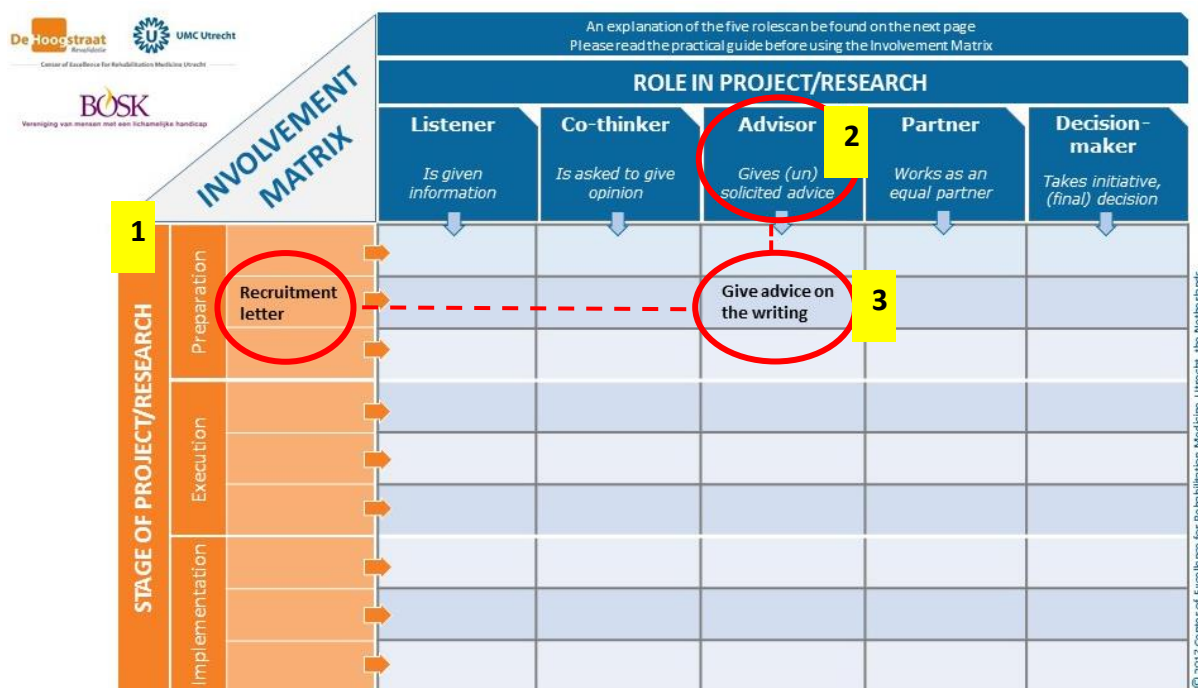
Example 2: Form for planning dialogues and noting agreements

During a project, this form can be further and more extensively completed. As an illustration, it has been filled in briefly in red italics (based on the example above)

Phase/sub-phase	Date of dialogue	Results: what arrangements have been made?		
		Role and content of activity	Period of role and activity	Follow-up dialogue(s)
Preparation: - *Recruitment letter*	*01/10/2017*	*Advisor: 'Patient gives advice on writing recruitment letter for respondents'*	*Between 01/10/2017 and 01/11/2017*	*01/11/2017: look back at advice on letter and look forward to the next phase and role*
Execution - …	…	…	…	
Implementation - …	…	…	…	