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PATIENT INVOLVEMENT – KCE PROCESS BOOK ANIMATION TECHNIQUES FOR BETTER PATIENT INVOLVEMENT

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■ ANIMATION TECHNIQUES FOR BETTER PATIENT INVOLVEMENT

1 INTRODUCTION - WHY SHOULD ANIMATION TECHNIQUES BE USED?

"Animation techniques are useful to make the collaboration more effective and comfortable. While for researchers and health professionals it is common practice to perform work meetings and share their perspectives, it might be intimidating for patients to have to share their opinions in a 'classical' work meeting where everyone sits at a table and is faced to all other collaborators. By using animation techniques, you could also "break the ice" and help each participant to feel at ease. It helps people to get to know each other, which is particularly critical when the patient involvement is planned to take several months or years. Moreover, such techniques may help to overcome the loss of concentration. The animation techniques can be used in every collaboration context at KCE (not only with patients but also with non-professionals). Other techniques exist and may always be adapted to the KCE context. We would therefore advise the researchers to test the technique beforehand to ensure the smoothness of its use during the discussion" (retrieved from Kohn et al. 2021). It should also be noted that besides for patient involvement some of these techniques can also be used for data collection purposes.

Table 1 presents the articulation between the methods selected to involve patients (columns) and the animation techniques (rows). For more information about the methods, please consult the Patient Involvement process note¹. In the following sections, each technique is described, including the material needed, the advantages and the points of attention. References to other work are provided for the interested readers who want to know more about a specific technique.

Table 1 – Animation techniques according to the method selected to involve patients

| | Delphi process | Steering committee | Open forum | Questionnaires & surveys | Nominal group | Work meetings |
|------------------------------|--------------------------------|--------------------|------------|--------------------------|------------------|------------------|
| Brainstorming | (1st round) | Х | Х | | | Х |
| Futures wheel | | | Х | | Х | Х |
| Group Analysis | | Х | | Х | Х | Х |
| Make a wish | | Х | Х | | | Х |
| Mind mapping | | Х | Х | | Х | Х |
| Netmapping | | Х | Х | | Х | Х |
| Patient / user journey | Х | Х | Х | Х | Х | Х |
| Photoscan / photovoice | (1 st round) | | | | | Х |
| Problem definition worksheet | Х | Х | Х | Х | х | Х |
| Problem tree | | | Х | | Χ | Х |
| Rich picture | | Х | | | Х | Х |
| Stakeholder identification | Х | Х | Х | Х | Х | Х |
| Stakeholder analysis | Х | Х | Х | Х | Х | Х |

2 HOW TO CHOOSE THE ANIMATION TECHNIQUE?

2.1 Depending on the project phase

While all techniques can be used for data collection purposes, they are not necessarily all suitable for patient involvement in all steps of the project. While some techniques could be fully applied, some require adaptations depending on the phases of the project: details are provided for each technique in the following sections.

Table 2 - Animation techniques according to the phases of a KCE project

| Animation technique | Project phases | | | | |
|--------------------------------|----------------|--------|----------|---------------|--|
| | scoping | design | analysis | dissemination | |
| BRAINSTORMING | Х | Х | Χ | Χ | |
| FUTURES WHEEL | Х | | | | |
| GROUP ANALYSIS | | | Х | | |
| MAKE A WISH | Х | | | X | |
| MIND-MAPPING | Х | Х | Х | Х | |
| NET-MAPPING | Х | Х | Х | Х | |
| PATIENT JOURNEY / USER JOURNEY | Х | | Х | | |
| PHOTO-SCAN & PHOTO-VOICE | Х | | | | |
| PROBLEM DEFINITION WORKSHEET | Х | | Х | | |
| PROBLEM TREE | Х | | Х | | |
| RICH PICTURE | Х | Х | Х | | |
| STAKEHOLDER ANALYSIS | Х | Х | Х | Х | |
| STAKEHOLDER IDENTIFICATION | Х | Х | Х | Х | |

2.2 Depending on the practical aspects

Needs in terms of human resources and time constraints vary from one technique to another. These must be taken into account when choosing the animation techniques, and considered in view of the planning and timing of the research project.

| | Easy to apply in virtual | Compatible with online interface (i.e. Miro) | Technical support | Preparation time for the researcher | Individual preparation time for the participant | Session duration |
|-----------------------------------|-----------------------------|---|---------------------------------------|---|--|-------------------------|
| BRAINSTORMING | +++ | Х | I | 15 min' | 1 | 15-60 min' |
| FUTURES WHEEL | + | Х | Futures wheel template | 3h | 1 | 2h |
| GROUP ANALYSIS | + | | Audio-recorder or smartphone | 1 week | 1h | ½ to 1 day per analysis |
| MAKE A WISH | ++ | | Ì | 8 weeks | / | 2-3h |
| MIND-MAPPING | ++ | Х | 1 | 3h | 1 | 1h-3h |
| NET-MAPPING | + | Х | "Checkers" | 3h | 1 | 1 day |
| PATIENT JOURNEY / USER JOURNEY | ++ | Х | Personas | 2 weeks | 1 | 1.5h/journey |
| PHOTO-SCAN & PHOTO- VOICE | + | | Camera or smartphone | 2 weeks | N days | 2h- 3h |
| PROBLEM DEFINITION WORKSHEET | +++ | Х | Problem worksheet template | 3h | 1 | Min. 3h |
| PROBLEM TREE | +++ | Х | Template shaped as a tree | 3h | / | ½ day |
| RICH PICTURE | ++ | Х | Magazines, scissors, coloured markers | 1h | 1 | Min. 1.5h |
| STAKEHOLDER ANALYSIS | ++ | Х | Stakeholder template | 1h | (1h to 2h) | 0.5 to 1h |
| STAKEHOLDER IDENTIFICATION | ++ | Х | 1 | 1h | 1 | 1h |

This is a living document: please share your experiences in using the technique

3 ANIMATION TECHNIQUES

3.1 Brainstorming

| 5.1 Drainst | |
|------------------------|--|
| | |
| What is it? | A group creativity technique by which efforts are made to find a conclusion for a specific problem by gathering a list of ideas spontaneously contributed by its members. This technique was popularised by Alex Osborn in the sixties and led to several techniques of group creation. |
| Objectives | To collect a wide range of ideas: brainstorming allows for submitting "wild" ideas, stimulating creativity, evidencing divergences ² |
| When to use it? | At any stage of the research process to prepare a more formal meeting Scoping phase: to generate ideas and questions about the issue at stake Design phase: to identify creative approaches to collect the data Analysis phase: based on collected data, to identify creative solutions Dissemination phase: to identify channels of dissemination |
| How long? | From 15 minutes to 1-hourEnd when saturation is reached |
| How many participants? | No defined number of participants The more participants, the longer the brainstorm lasts: consider splitting in groups of 8 to 12 participants to ensure participants of all |
| How many researchers? | 1 moderator1 note-taker |
| What do you need? | Markers, sticky notes and whiteboard Online interface (i.e. Miro, Padlet) (Speech staff with large or "turbulent" groups) |
| How to? | - Before |
| | Define clearly the objective(s) of the brainstorming |
| | - During |
| | (facultative) allow for an individual time of reflexion to help participants to prepare themselves – could be done before |
| | Foster an inclusive, supportive environment. "No bad ideas" has become a brainstorming cliché, but if someone's idea gets shot down quickly, they are less likely to have the confidence to share their next. |
| | o Dynamic version |
| | Participants write their ideas on a sticky note and put it on a board |
| | The moderator asks the participants to read their idea or reads it her/himself |
| | o Immobile version |
| | Participants speak their ideas out loud |
| | An animator writes down the ideas After |
| | After Moderator needs to help participants to recognize that a brainstorm serves a purpose, which is to foster new ideas, solutions, products, etc., |
| | The participants need to follow up in order to bring these ideas to life. |
| | Moderator needs to make sure to set up ample time to narrow down the ideas shared by the participants and pursue a few in a structured |

manner.2

Advantages

- Easy to use, cheap and well-known
- Could be "improvised" at any time during the project
- Boost the group moral by creating team bonding
- Promote creative thinking
- Bring together diverse and a large quantity of ideas
- Useful when a team is "stuck"

Attention points

- Need an experienced moderator to ensure participation of all
- Unbalanced discussion when strong personalities dominate it
- "Anchoring effect": risk of convergence towards the first few ideas brought up in the beginning
- Awkward silences

Extra tips

- Use string or wool to weave the connexions between ideas
- Invite external participants to bring new ideas
- Change of scenery: do not hesitate to conduct the brainstorming in a new place to foster creativity
- Use speech staff to share the floor: only the participant having the "speech staff" (any object chosen by the moderator) is allowed to speak. The speech staff circulates between the participants.

- Round-robin brainstorming:

- o Contribution by every member of the meeting
- First rule: the group has to make it around the whole room at least once before anyone can contribute a second idea or criticize, elaborate on, or discuss any of the ideas.
- Second rule: no one can say, "My idea was already said." You can come back to that person at the end when they've had more time to think. It's also a good idea to give the team some time to prepare ideas before the brainstorm meeting.²
- **Rapid ideation**: in a set time constraint, writing down as many ideas as possible before any discussion ².

- Figure storming:

- Choice of a well-known figure who is not in the room—it could be a boss, a fictional character, or a well-known public figure
- Discussion about how that person would approach the problem or think about this idea ².

Step-ladder technique:

- Introduction of the topic by moderator
- Everyone leaves the room except for two participants.
- First brainstorm between two participants during a few minutes
- o Arrival of a third person: add new ideas
- Arrival of participants one by one until end
- While waiting outside: individual brainstorming, no discussion between participants (²)

To go further

http://www.brainstorming.co.uk/

https://en.wikipedia.org/wiki/Brainstorming

 $\underline{\text{https://www.wrike.com/fr/blog/13-applications-de-brainstorming-et-outils-pour-}}\underline{\text{stimuler-linnovation/}}$

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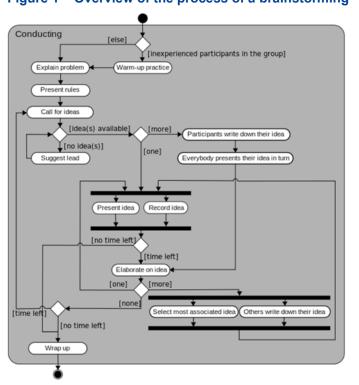


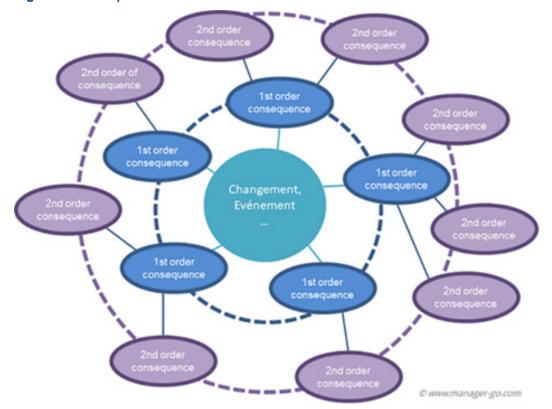
Figure 1 – Overview of the process of a brainstorming³

3.2 Futures wheel

| NAM . 4 : 240 | |
|------------------------|---|
| What is it? | The Futures Wheel is a simple, practical tool, useful to brainstorm about the direct and indirect consequences of a decision, event, or trend . Inspired by the prospective research trends, this tool allows the collective visualization, analysis and exploration of the indirect and direct consequences of a change, an event, a problem or a trend. It then supports decision-making while taking into account the potential consequences. It provides a framework for a creative discussion about the future. |
| Objectives | - To graphically represent consequences of change |
| | - To anticipate resistance to change |
| | - To get insights that can help to prevent or limit risks |
| When to use it? | Scoping phase: to identify areas of the issue that should be investigated, including those having potential negative consequences |
| How long? | Depending on the complexity of the event/decision/trend |
| How many participants? | - 8 to 12 participants |
| How many | - 1 moderator |
| researchers? | - 1 note-taker |
| What do you | - Flipchart / piece of paper |
| need? | - (Online software) |
| | - (Predefined templates) |
| How to? | - Step 1: Identify the change |
| | Write the change/event/problem/solution to consider in the centre of a piece of paper, or on a flipchart |
| | - Step 2: Identify direct and first-order consequences |
| | Brainstorm on the possible direct consequences of that change |
| | Write each consequence in a circle |
| | Connect the consequence to the central idea with an arrow = "first- order" consequences |
| | - Step 3: Identify indirect and second-order consequences |
| | Brainstorm on all the possible "second-order" consequences of each of the first-order (direct) consequences written down |
| | Add the second-order consequences to the diagram |
| | Repeat the process until saturation is reached |
| | - Step 4: Analyse the implications |
| | Once saturation is reached: picture the possible direct and indirect consequences resulting from the change |
| | Make a list of the consequences |
| | - Step 5: Identify actions |
| | For negative possible consequences: identify how to manage them For positive possible consequences: identify how to improve them |
| Advantages | - Easy to use and understand |
| J | - Universal tool, suitable for numerous topics |
| | - Help to frame and structure impacts |
| | - Creative framework for the collective explorations of consequences |
| | |

| | - Allows for interactions and debates in a group |
|------------------|---|
| Attention points | Risk of missing some consequences that are not related to the first wheel Simplification of the relationships between the consequences Some consequences may be difficult to project and anticipate Distinction between primary or secondary impact could be difficult |
| Extra tips | Carefully define the issue that needs to be explored Prepare an interview guide to prompt the discussion Use of colour-code for each "level" of the wheel: easier to prioritize and analyse consequences at the end Not all consequences are negative |
| To go further | Bengston D. The Futures Wheel: A Method for Exploring the Implications of Social—Ecological Change. Society & Natural Resources. 2015;29:1-6. Daffara P. Applying the Futures Wheel and Macrohistory to the Covid19 Global Pandemic. Journal of Futures Studies. 2020;25(2):35-48. |
| Online demo | Application to the Covid19 pandemic via Miro (25 min.) |
| @KCE | |

Figure 2 – Example of a Futures Wheel



3.3 Group analysis

| WII | |
|------------------------|---|
| What is it? | Groups of around 12 persons analyse together situations and experiences as reported by participants themselves, based on a rigorous and precise methodological process piloted by the researchers. Round table after round table, each participant proposes her/his interpretation of the analysed experience. Divergences and convergences are systematically discussed and included in a synthetic scheme. From this schema, participants and researchers confront their hypotheses and attempts to problematize the issue. These could be explored and deepened thorough the collective analysis process of the experiences and situations. This method, at the difference of the group interview or the focus group, involves participants in the analysis phase (Adapted from Van Campenhout et al. 2009) ⁴ . |
| Objectives | To stimulate the reflexivity of the participants as social actors involved in social relationships with other actors in social situations and institutional contexts |
| | To articulate the integration of the diversity of the experiences and to elaborate a common analysis for reconstructing an action system in which participants are stakeholders (Adapted from Van Campenhout et al. 2009)⁴ |
| When to use it? | Analysis phase: experiences of participants serve as material to be analysed |
| How long? | - At least one day per analysed experience |
| How many participants? | - Max. 12 per group |
| How many researchers? | - 1 moderator |
| | - 1 note-taker |
| What do you need? | - Audio-recorder |
| How to? | - First phase : the story |
| | - Proposal of experiences by the participants (pitch presentation) |
| | - Choice of the experiences that will be analysed |
| | Experience telling (long narration of the chosen experience audio-recorded) |
| | - Challenges as seen by the narrator |
| | - Information questions by the other participants |
| | - Second phase : interpretation |
| | First round table where participants propose his/her analysis of the reported experiences in 2-3 minutes |
| | - Reactions of the narrator |
| | (facultative) new listening of the story by the narrator thanks to the recording |
| | Second round table where participants propose new interpretations of the experiences: they may react to the proposals of the others |
| | - Reactions of the narrator |
| | - Third phase:analysis |
| | Convergences and divergences: the note-taker proposes a synthesis of the interpretations by themes illustrating convergences and divergences |

| Online demo @KCE | |
|-------------------|--|
| To go further | Van Campenhoudt L, Franssen A, Cantelli F. (2009). La méthod d'analyse en groupe », Sociologies https://doi.org/10.4000/sociologies.2968 |
| Extra tips | Could be used in combination with other methods such a comprehensive interviews, questionnaires or observation |
| | - The more groups, the more workload |
| | Participants need to receive a report after each partial analysis so that they could prepare themselves for the new session |
| | Needs a cautious selection of the participants to ensure well-balanced group |
| | - Requires abstraction and personal reflexivity |
| Attention points | - Requires sufficient time for the collective analysis |
| | Take into account the relational dimensions of the studie issues |
| | - Bottom-up approach |
| | Highlight the cooperative and conflictual dimension of the social issues |
| | Combination of the personal involvement and the distant of the collective analysis |
| | - Allow for studying diverse and complex issues |
| Advantages | - Suitable for heterogeneous groups |
| | Evaluation: after each partial analysis, a feedback is necessary to ensure the wellbeing of the participants |
| | done after each analysis phase |
| | - Formulation of practical perspectives: this doesn't need to be |
| | Proposal of hypotheses by the researchersFourth phase: practical perspectives and evaluation |
| | Theoretical contributions by the researchers: to precise key concepts useful for the analysis or to frame the issue in the current state of the art of the knowledges. |

3.4 Make a wish

| What is it? | Based on the appreciate storytelling approach, this technique aims at transforming critics into wishes for the future. Appreciative storytelling aims at encouraging a positive perspective on a situation. |
|------------------------|---|
| Objectives | To clarify demands and needs To identify solutions for improvement To identify good practices |
| When to use it? | Scoping phase: could serve as an "orientation visit" when the issue is poorly known or that no clearly patient association is identified Dissemination phase: to help carrying a positive message around the results of the study |
| How long? | 6 to 8 weeks + 8 weeks for preparation 3 meetings per group of participants (one meeting per step) |
| How many participants? | 3 to 12 participants per group Participants are selected based on their personal and/collective experience of the issue |
| How many researchers? | 1 moderator1 note-taker |
| What do you need? | - Interview guide |
| How to? | First step: open group discussion First meeting Each participant shares his/her experiences Moderator makes the inventory of the individual experiences Moderator concludes the discussion by a synthesis in 15 key points Second step: guided group discussion Second meeting Based on the 15 key points, the moderator helps to reformulation the key points into wishes / solutions Participants have to agree on the wishes (Third step: formulation of recommendations) Facultative step Third meeting Based on the wishes, participants transform into actions (adapted from PAQS 2018⁵) |
| Advantages | Creates a positive dynamic into the group Useful to help orienting the solutions Suitable for patients not belonging to a patient association: persons attending the same service independently of their conditions, consumer group, persons sharing a same social condition (e.g. asylum seekers, young mothers, etc.) |
| Attention points | Time consuming Requires an experienced moderator Requires rapid analysis between the sessions |

| Extra tips | |
|---------------|--|
| To go further | PAQS asbl. Participation du patient/résident. Aperçu d'outils et méthodologies. Bruxelles: PAQS; 2018. |
| @KCE | |

3.5 Mind-mapping

What is it?

A mind-map is a quick method to gather ideas at the pace they come to the mind, without paying attention to their order, and then to visually structure them to facilitate analysis. This serves for the intuitive organisation of ideas, tasks, words or concepts related to a central issue. Mind maps are diagrams used to visual information. Mind maps are often created around a single concept, drawn as an image in the centre of a blank landscape page, to which associated representations of ideas such as images, words and parts of words are added. Major ideas are connected directly to the central concept, and other ideas branch out from those. Mind-mapping is usually an individual activity but could be done collectively.

Objectives

- To visually display information related to an issue in a non-linear way that allows for eliciting connexions and relationships between components & subcomponents
- To help to provide a preliminary framework of analysis
- To help to simplify a complex issue into more tangible tasks
- To solve more complex problems than an individual would do on their own
- To share stories
- To initiate diverse and creative thinking together
- To hear every voice in collaborative decision making.

When to use it?

- Scoping phase: could be done around the issue or the whole project to help planning activities
- Design phase: to map the different methodological options, to map the recruitment channels, to identify possible connexions between data collection activities
- Analysis phase: to connect data previously collected. In this case, the research team should make a first analysis of the data and use the mindmap to help interpret data.
- Dissemination phase: to identify priority axes for dissemination activities

How long?

- Duration will depend on the degree of details expected
- At least 1h but no longer than 3h to prevent loss of concentration

How many participants?

5 to 15 participants

How many researchers?

- 1 moderator
- 1 note-taker

What do you need?

- Online version: mindmap softwares (e.g. Miro, Mindmeister...)
- Face-to-face version: large paper sheet or a blackboard, sticky notes of various colours, markers and colours pens
- Examples of templates

How to?

- Basic rules
 - Defining a central idea start with a focus at the centre of the page
 - Active & attentive listening.
 - Drawing each mind map element with consensus after thorough discussions.
- First step: plotting sub-themes

- Define key areas related to the central areas (ideally less than 4 but it's theoretical, it will depend on the complexity of the issue)
- o Using colours or shapes to help visualisation

Second step: developing further & expanding

- At this stage, all the groundwork is done: participants can add as many ideas and levels as they want.
- Rely on key words
- Draw connections between key words
- Detail as much as possible before moving to another sub-theme
- Expansion could be done two ways:
 - Participants focus on a sub-group and fully populate it.
 - Participants focus on different areas at the same time.
- If necessary, add a whole new sub-group to the main focus: new ideas can emerge thorough the process.

Advantages

- Useful for those who think visually
- Possible online
- Integrating people to change processes, methods, maps, and planning tools
- Calling up the collective intelligence of a group.
- Identifying what is "behind" an issue

Attention points

- Supposes capacity to think abstractedly
- Online mind-mapping needs a good level of digital literacy
- Could take time

Extra tips

- Importance of the diversity of players
- Importance of the complexity of elements
- Consider putting a visual element at the centre of the mind-map to trigger imagination and foster discussion
- Do not hold back the ideas: elements are not static, they can be moved or erased in a later stage
- Record everything that you think of or that is discussed

To go further

- Buitron de la Vega P, Coe C, Paasche-Orlow MK, Clark JA, Waite K, Sanchez MJ, et al. "It's like a mirror image of my illness": Exploring Patient Perceptions About Illness Using Health Mind Mapping-a Qualitative Study. J Gen Intern Med. 2018;33(10):1692-9.
- Gossack-Keenan K, De Wit K, Gardiner E, Turcotte M, Chan TM. Showing Your Thinking: Using Mind Maps to Understand the Gaps Between Experienced Emergency Physicians and Their Students. AEM Educ Train. 2020;4(1):54-63.
- Rising KL, LaNoue M, Gentsch AT, Doty AMB, Cunningham A, Carr BG, et al. The power of the group: comparison of interviews and group concept mapping for identifying patient-important outcomes of care. BMC medical research methodology. 2019;19(1):7-.
- Yu HW, Hussain M, Afzal M, Ali T, Choi JY, Han HS, et al. Use of mind maps and iterative decision trees to develop a guideline-based clinical decision support system for routine surgical practice: case study in thyroid nodules. J Am Med Inform Assoc. 2019;26(6):524-36.

Online demo

<u>Creating a mind-map with PowerPoint (10 min.)</u> Short Miro tutorial for mind-map (<2 min.)

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3.6 Net-mapping

| What is it? | Net-Map was developed by the International Food Policy Research Institute (IFPRI) to help understand and visualize how stakeholder goals work out in an MSP. This tool helps stakeholders to determine which actors are involved in a given network, how they are linked, how influential they are, and what their goals are. It is a hands-on social networking tool ⁶ .Net-mapping is an animation technique mixing the principle of the social network analysis and the power mapping tool: participants draw a map of all the actors concerned by the issue, identify relationships between them and build "influence towers" to transfer abstract concepts of power and influence into a three-dimensional form. |
|------------------------|--|
| Objectives | To help people understand, visualize, discuss, and improve situations in which many different actors influence outcomes. To provide an influence network map of the governance situation |
| When to use it? | Scoping phase: to identify actors and their interests in the issues, could be interesting for projects based on stakeholder perspectives Design phase: to identify participants and recruitment channels Analysis phase: to map networks from data and help interpreting data Dissemination phase: to identify actors to be informed |
| How long? | 1 day |
| How many participants? | 5 to 6(if large groups, consider splitting it in smaller groups) |
| How many researchers? | 1 moderator 2 note-takers: 1 for the overall discussion 1 to list the responses of the participants |
| What do you need? | Flipchart paper to draw the map Sticky notes or labels to write the names of actors Flat round stackable discs for building influence-towers (e.g. checker's pieces, bicycle spare parts) Alternatively: stones or beans (Actor figurines - different board game figures, optional but especially useful when working with illiterate interviewees) Markers of different colours to draw the links between actors ⁶ |
| How to? | Preparation by the research team Define questions (e.g. "Who can influence the patient trajectory?"). Define links (e.g. giving money, disturbing someone, giving support, giving command) Assign different colours to the links (i.e. giving money = red link). Define goals (e.g. pro and contra a change of legislation, pro and contra a new patient trajectory). Decide who should be involved in interviews/discussion (participants) |

- Moderator: explain the different codes
- Ask participants to list all participants involved in the issue
- Note-taker writes names on actor cards and place it on an empty Net-Map sheet

- Drawing of links- with participants

- Ask the participants to identify the link between participants
- Participants go through the different kinds of links one by one (e.g. "Who gives money to whom? Who disturbs whom?").
- Note-taker draws arrows between actor cards according to participants directions.
 - If two actors exchange something (e.g. information) draw double headed arrows.
 - If actors exchange more than one thing, add differently coloured arrow heads to existing links.

- Influence Towers with participants

- Ask "How strongly can actors influence xy?"
- Moderator explains/agrees on a definition of influence with the participants
- Moderator needs to clarify that this is about influence on xy and not influence in the world at large.
- Ask participants to assign influence towers to actors:
 - The higher the influence on the issue at stake, the higher the tower (or alternatively, the more stones or beans).
 - Towers of different actors can be of the same height.
 - Actors with no influence can be put on ground level.
 - Towers can be as high as interviewees want.
- Note-taker places influence towers next to actor cards.
- Moderator should ask participants to verbalize set-up and give participants the chance to adjust towers before noting height of tower on the Net-Map (important for documentation purpose).

- Goals with participants

- Ask according to pre-defined goals, actor by actor, e.g. "Does this actor support vertical equity in health care, horizontal equity or both?"
- Note-taker notes abbreviations for goals next to actor cards:
 - allow for multiple goals where appropriate, by noting more than one goal next to the actor.

Discussion with participants

- According to specific goal of the Net-Map exercise, discuss what this network means for strategy of organization, where influence comes from, what happens in case of conflicting goals etc.
- If multiple groups, plan time for a plenary discussion (section adapted from Brouwers 2017⁶)

Advantages

- Low tech and low cost
- Could be used with patients with little formal education
- Provides qualitative and quantitative data about the perceived power and influence of the actors.
- Useful for projects with a policy dimension
- Makes positions and roles inside a network visible

| Attention points | Participants need to have a good knowledge of the actors Maybe difficult to assess the boundaries of the network Homogeneous group of participants may quickly reach saturation The bigger the group, the smaller the inputs for individuals |
|------------------|---|
| Extra tips | Useful in a mixed audience, not only patients Depending on the issue, a first round of individual net-map could be done before going into a group discussion: this allows for focusing on actors that only have been mentioned in the interviews Possible to convert it in social network analysis data via software like Ucinet or Pajek. |
| To go further | Schiffer E. Net-map toolbox. Influence mapping of social networks. 2007. Schiffer E, Hauck J. Net-Map: Collecting Social Network Data and Facilitating Network Learning through Participatory Influence Network Mapping. Field Methods. 2010;22:231-49. Wijenberg E, Wagemakers A, Herens M, Hartog FD, Koelen M. The value of the participatory network mapping tool to facilitate and evaluate coordinated action in health promotion networks: two Dutch case studies. Glob Health Promot. 2019;26(3):32-40. |
| Online demo | |
| @KCE | |

3.7 Patient journey / user journey

What is it? Patient journey lies on the following principle: "An experience or a feeling isn't siloed, yet infrastructures and responsibilities are very siloed. A user journey reconnects everything in order to optimise the experiences as a whole". In other words, a patient journey depicts all the stages in a trajectory that a patient encounters in a particular care situation. This technique is used i.e. by health care services to improve patient experience and quality of the patient trajectory but could be also used for research purposes. **Objectives** To visualise all steps a patient encounters in a defined situation in order to uncover interactions, To learn from these interactions To better understand what happens in the process When to use it? Scoping phase: to focus on specific aspects of an issue and identify specific research questions / objectives Analysis phase: based on previously collected data, the patient journey could serve as a template to make the results more practical and more comprehensible. How long? Depending on the complexity of the journey At least 1.5 hour per journey How many Not defined participants? 8 to 12 participants 1 moderator How many researchers? 1 note-taker What do you Could be done online (e.g. Miro, Mindmeister, ...) need? A persona depicting a patient story Flipchart & sticky notes (facultative: predefined templates. Examples templates: https://www.mindmeister.com/blog/ux-design-process-mind-maps) How to? Decide on the type of journey Existing experiences to be improved: in this case, the journey starts by describing the current situation and aims at describing the ideal situation. This is the most common type of journey. Developing an entirely new experience: in this case, the journey is developed as the participants wanted it to be, with a focus on the future without any restrictions. This kind of journey is more suitable for prospective research or innovative projects starting from a blank sheet. Create a persona: who's experience are you mapping? Several personas could be needed as the journey may concern different target groups or situations Who is in need of care: are there multiple patients that need their own trajectory? (e.g. child, adult, elder,...) Is there any expectation that these patients will have a different experience? What

populations are experiencing flow problems, and what are their needs? Differentiate among the major subgroups with different clusters of need; prioritise those that account for the greatest amount

of potentially conservable utilisation.7

- What do they need: are there multiple services / situations that need their own trajectory? (e.g. acute care, chronic care, prevention...)
- **Discuss the beginning of the journey**: where does the story begin and why does it start here / where it ends (e.g. is the journey starting when the patient leaves its home or does the journey stars when entering the reception hall of the hospital, is the journey ending when the patient feels better or when the patient takes the first dose of the prescribed treatment)
- Identify the high levels / key stages : make them as detailed as possible if it is relevant (e.g. identify the actors involved in the stages)
 - **How do they get there ?** (process) What process does this population currently experience? Map the process, using data to locate the prime constraint that impedes or delays access to suitable capacity; the process' endpoint should be defined as the point at which the identified needs have been met.⁷
- Add context to the journey: tell the story of the persona and capture small frictions that the persona encounters at this stage (e.g. how the persona is feeling in the situation, how the friction is materialised in the persona experience)
- Select the most crucial phases in the journey and try working out a solution around that phase
 - What capacity is most suitable for meeting the identified needs, bearing in mind that different capacity may be required as patients' needs evolve? If appropriate, consider multiple suitable options, noting which ones are already present in the system.⁷
 - What alternative process(es) could straightforwardly link the population to suitable capacity, avoiding the constraint? If new capacity and/or processes are proposed, how will these impact other populations? What is needed to ensure that new or released capacity is used for its intended purpose?⁷
- If conducting several journeys, identify which stages are common / which stages are different

Adapted from Kreindler et al. 2017⁷

Advantages

- Visual representation of the process
- Could include data from other sources: interviews, literature, etc.
- Allow for prioritisation of the problems and actions
- Support implementation of actions
- Help to clarify complex systems
- Could be also used with individual patients as data collection
- Could be used as a strategic tool for organisational improvement

Attention points

- Clearly define the target population at the beginning before discussing the journey
- Include both patients process capacity to prevent flaws
- Take time to identify the most critical problems in the process to improve efficiency
- Include the temporality in the process to match the duration of population needs (e.g. do not end patient journey at the reception of the prescription as patient may still encounter barriers to access the pharmacy)
- Define the persona should be carefully done as it may reduce the scope

Extra tips

Create the personas could be done by the research team but could also be done with the participants: in that case, process will take longer

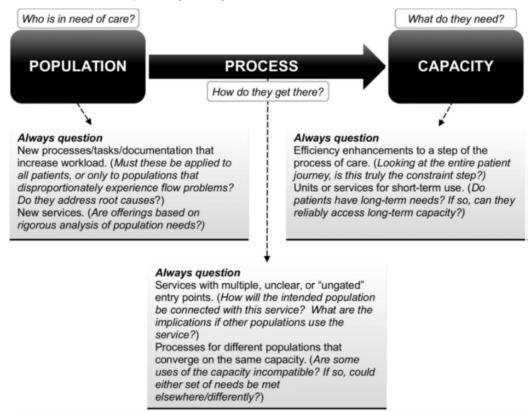
- Don't need to be complex: if too complex, consider making a new journey
 Just need enough details
 Discussion should lead to observations and opportunities
- To go further
- Bharatan T, Devi R, Huang PH, Javed A, Jeffers B, Lansberg P, et al. A Methodology for Mapping the Patient Journey for Noncommunicable Diseases in Low- and Middle-Income Countries. J Healthc Leadersh. 2021;13:35-46.
- Kalantari M, Hollywood A, Lim R, Hashemi M. Mapping the experiences of people with achalasia from initial symptoms to long-term management. Health Expect. 2021;24(1):131-9.
- Kreindler SA. Six ways not to improve patient flow: a qualitative study. BMJ Qual Saf. 2017;26(5):388-94

Online demo Conference (30 min.)

Short demonstration using Miro Long demonstration using Miro

@KCE

Figure 3 - Overview of a patient journey



Retrieved from Kreindler, 2017⁷

3.8 Photo-scan & photo-voice

| What is it? | Photo-scan, also called photo-voice, is a process by which people can identify, represent, and enhance their community through a specific photographic technique (8). |
|------------------------|--|
| Objectives | To collect experiences by using visual support, making it more tangible. To enable people to record and reflect their community's strengths and concerns To promote dialogue and knowledge about important issues through large and small group discussion of photographs To support needs assessment for patient perspectives To gather data on poorly studied issues, in settings, moments and ideas that are less accessible to researchers |
| When to use it? | Scoping phase: this could serve as an "orientation visit" / "exploratory interview" |
| How long? | Depending on the issue at stake |
| How many participants? | Not specified but as it involves a group discussion, pay attention to the final number of participants |
| How many researchers? | 1 moderator 1 note-taker 1 contact person in charge of keeping contact with participants during photo reportage and debrief participants during this stage |
| What do you need? | Cameras or mobile phones with a camera Individual interview guide Group interview guide Display support to share the pictures |
| How to? | Participants are invited to take or bring pictures illustrating their experiences; Participants justify their choice during an individual interview (or record it directly when taking the pictures to prevent memory bias); A group discussion is organized to discuss pictures and related issues, with participants having taken / not having taken pictures. |
| Advantages | Provide real life data Useful with patients with low literacy or speech problems Easy to use in various contexts Allow for capturing time and space variations inside an issue |
| Attention points | Costly and time-consuming Allow sufficient time so the participants could prepare the meeting Subjective dimension +++ May be difficult to be put in common Confidentiality and consent |
| Extra tips | Photo material could be prepared by research teams and serve as a basis for discussion Plan a training session on how to use the camera Plan regular contacts with the participants to prevent drop-outs |

- Capewell C, Ralph S, Symonds M. Listening to Women's Voices: Using an Adapted Photovoice Methodology to Access Their Emotional Responses to Diagnosis and Treatment of Breast Cancer. J Patient Exp. 2020;7(6):1316-23. - Han CS, Oliffe JL. Photovoice in mental illness research: A review and recommendations. Health. 2016;20(2):110-26. - Wang C, Burris MA. Photovoice: concept, methodology, and use for participatory needs assessment. Health Educ Behav. 1997;24(3):369-87. Online demo American community health projects using photo-voice (7 min.) How to make a photo-voice ? (8 min.)

3.9 Problem definition Worksheet

| What is it? | The Problem Definition Tool works both to open a problem up and to help define the wider context and associated issues involved. It examines the evidence and the assumptions underlying the problem. Such a detailed examination can sometimes lead to the problem being completely reframed. Often what seems to be the problem is only a symptom of a deeper problem. This tool helps to understand the dimensions of the problem, by looking at it from different angles. You can apply it individually, but also do this with a group of stakeholders as a way to bring ideas towards a similar direction. At the very least, the tool will lead to a more rigorous and critical definition, captured in a statement that is both explicit and succinct. A problem definition set out in one well-formulated sentence is very valuable: something that addresses the central elements of the issue ⁶ . |
|------------------------|--|
| Objectives | To analyse the problem you are working on To bring ideas in a similar direction To look at a same issue from different perspectives and angles |
| | - To rephrase a problem to make it clearer to solve |
| When to use it? | Scoping phase: based on experiences of the participants, this helps to identify the different aspects to be studied: this may help to define the specific objectives of the research. Analysis phase: based on the data collected, the participants help to |
| | organise it in a meaningful way. This will help to discuss about solutions. |
| How long? | Depends on the issue – 3h at least – could be split according the steps of the framework |
| How many participants? | - 8 to 12 participants |
| How many researchers? | 1 moderator1 note-taker |
| What do you need? | Flip chart – sticky notes Could be done online Pre-established frameworks are available |
| How to? | This technique relies on a structured question framework starting from the definition of the problems to the formulation of solutions and recommendations. By using this systematic questioning, participants are invited to stay focused on the issue at stake. |
| Advantages | Structured and systematic process Allow for multiple stakeholders inputs Could be informed with evidence from the literature |
| Attention points | Requires sufficient time to go into details Requires to close a step before moving forward Not all processes are linear |
| Extra tips | - Allow participants to prepare the discussion by informing them beforehand |
| | Add evidence from other sources to support the discussion: collected data could i.e. inform the first step of the process |

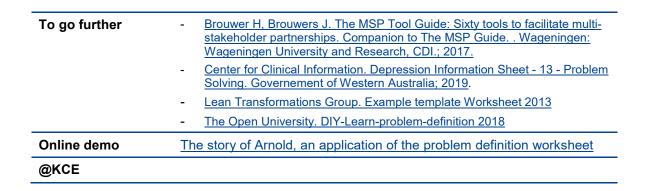


Figure 4 - Flow chart of problem definition tool9



Retrieved from the Open University, 2018{The Open University, 2018 #71}

3.10 Problem tree

| What is it? | Problem tree analysis (also called Situational analysis or just Problem analysis) helps to find solutions by mapping out the anatomy of cause and effect around an issue in a similar way to a Mind map, but with more structure. This technique uses the allegory of a Tree to make it more tangible. |
|------------------------|--|
| Objectives | To create a structural (and visual) analysis of the causes and effects of an issue or problem |
| | To help identifying priorities |
| When to use it? | Scoping phase: similar to the problem definition worksheet, will help to clarify objectives and research questions. |
| | Analysis phase: based on collected data, this could help the interpretation of data by organising it in a more meaningful way |
| How long? | Half a day depending on the complexity of the issue |
| How many participants? | - 6 to 8 participants |
| How many researchers? | - 1 moderator |
| • | - 1 note-taker |
| What do you need? | Flip chart paper or overhead transparency with the draw of a tree |
| | Sticky notes (use colours to distinguish causes and consequences) |
| | - Could be done online: Miro, Padlet, |
| How to? | Step 1: Discussing and agreeing on the problem / issue to be analysed |
| | Write the problem in the centre of the flip chart= 'trunk' of the tree = 'focal problem' |
| | Step 2: Identifying the causes and consequences of the focal problem |
| | Write down causes on sticky notes = roots |
| | Write down consequences on sticky notes (another colour) = branches |
| | - Could be done individually or in pairs |
| | Organise the sticky notes in a cause and-effect logic Moderator's role: |
| | - Ensuring that there is a discussion, debate and dialogue generated in the process of creating the tree. |
| | Allowing people to explain their feelings and reasoning, and record related ideas and points that come up on separate flip chart paper under titles such as 'solutions', 'concerns' and 'dilemmas'. |
| | (adapted from Brouwer 2017 ⁶) |
| Advantages | Enabling clearer prioritisation of factors and helping focus on objectives by breaking an issue into chunks |
| | Increased understanding of the problem and its often interconnected and sometimes contradictory causes: first step in finding win-win solutions |

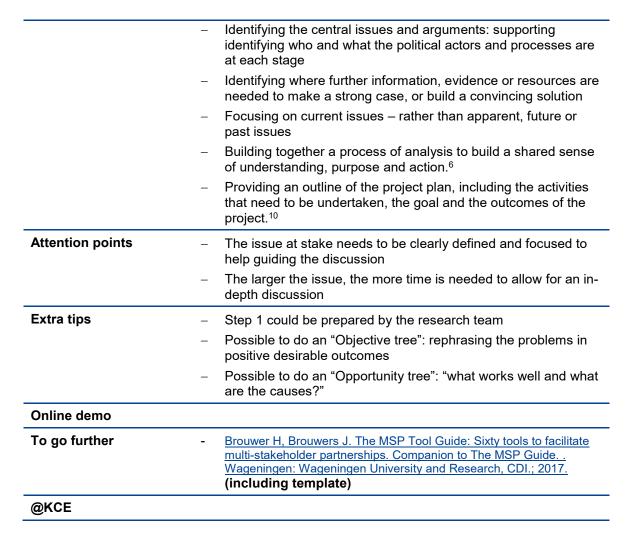
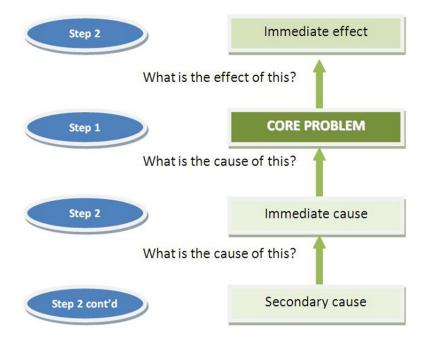


Figure 5 – Overview of a Problem Tree ¹⁰



3.11 Rich Picture

What is it? A rich picture is a drawing of a situation that illustrates the main elements and relationships that need to be considered in trying to intervene in order to create some improvement. It consists of pictures, text, symbols and icons, which are all used to illustrate graphically the situation. It is called a rich picture because it illustrates the richness and complexity of a situation. [....] It is a way of thinking holistically. It is based on the idea that 'a picture tells a thousand words'. It also builds on the fact that our intuitive consciousness communicates more easily in impressions and symbols than in words. Drawings can both evoke and record insights into a situation. **Objectives** To understand the complexity of an entire situation. To see relationships and connections that we may otherwise miss To identify one or more themes participants may want to further explore and address. When to use it? Scoping: to clarify the issue and the different connexions; this will help to clarify the research questions and objectives Design: to envision different methods, to map the recruitment process or the target groups Analysis: based on collected data, to identify solutions and their consequences How long? At least 1.5 hours 5 to 7 persons How many participants? Several Rich Pictures could be done in parallel How many 1 moderator researchers? Large piece of flip chart paper or brown paper or paper tablecloth What do you need? A table to put the paper on OR on the group Markers (one colour per participant) Could be done online How to? Chose a case Draw in the centre the problematic situation (=current situation) Start drawing, don't start talking or discussing. Explain as you draw! Who are the stakeholders and how do they relate to the problematic or the issue? Draw the relations of stakeholders to each other. Draw the context, the causes and effects and any other relevant social, economic, political, environmental features or issues. Make sure your drawing includes both facts and subjective information. You can use a legend or some words to explain stakeholders or problems, but do not use too many words. Wrap up by writing down the 5 main challenges of the case arising from the rich picture. **Advantages** Participative collective activity as everyone can add to it and explain their particular interests or perspectives.

| | Non-threatening and humorous way of illustrating different perspectives and conflicts |
|------------------|---|
| | - Is included in specific research approaches as Systems Thinking |
| Attention points | Drawing and explaining simultaneously could be difficult for some participants |
| | This needs a well-trained moderator to ensure that the rule of drawing + explaining is respected |
| | Interpretation afterwards could be difficult by those who did not participate in the animation |
| | - Could be perceived as childish or too metaphoric by some participants |
| Extra tips | - Do not hesitate to bring magazines or other supports that the participants can use to voice their ideas (bring along glue tube, scissors, tape) |
| | Make people circulate in the room, avoid having them sitting around the table |
| | Rich picture could also be used in Systems thinking or for data collection purposes. |
| | - Note-taker with a taste for sketch note could be an asset |
| To go further | - Bood ZM, Scherer-Rath M, Sprangers MAG, Timmermans L, van Wolde E, Cristancho SM, et al. Living with advanced cancer: Rich Pictures as a means for health care providers to explore the experiences of advanced cancer patients. Cancer medicine. 2019;8(11):4957-66. |
| | - Conte KP, Davidson S. Using a 'rich picture' to facilitate systems thinking in research coproduction. Health research policy and systems. 2020;18(1):14- |
| | - Crowe S, Brown K, Tregay J, Wray J, Knowles R, Ridout DA, et al. Combining qualitative and quantitative operational research methods to inform quality improvement in pathways that span multiple settings. BMJ Qual Saf. 2017;26(8):641-52. |
| | Long JC, Gul H, McPherson E, Best S, Augustsson H, Churruca K, et al. A dynamic systems view of clinical genomics: a rich picture of the landscape in Australia using a complexity science lens. BMC Med Genomics. 2021;14(1):63. |
| Online demo | <u>Usefulness of rich pictures in health care (> 3min)</u> |
| | How to draw Rich Pictures (16 min.) |
| @KCE | |
| | |

3.12 Stakeholder analysis

| What is it? | "A stakeholder analysis is a process of systematically gathering and analyzing qualitative information to determine whose interests should be taken into account when developing and/or implementing a policy or program" (definition retrieved from Schmeer 1999 ¹¹). Making an Importance versus Influence Matrix helps to map out stakeholders and their relation to the issue at stake in a research project. It generates insights on the importance, that is the priority given to satisfying the needs and interests, and influence, that is the power a stakeholder has to facilitate or impede the achievement of an activity's objective, of each stakeholder. The influence is also defined as the extent to which the stakeholder is able to persuade or coerce others into making decisions, and following a certain course on action. ⁶ . |
|------------------------|--|
| Objectives | To capture the degree of influence and level of interest of each stakeholder over the relevant issues or possible objectives of the research |
| | - To identify (potential) stakeholders who might not yet be on board ⁶ . |
| When to use it? | Scoping phase: to help determining specific objectives and research questions |
| | Design phase: to identify participants that need to be involved in the data collection phase and to identify which strategy(ies) of data collection should be used for them |
| | Analysis phase: if data collected contain a wide range of actors, the stakeholder analysis could serve as a template to put information in a meaningful way Dissemination phase: to identify stakeholders to be informed and the |
| | most appropriate strategy to do so |
| How long? | 30 minutes to 1 hour, depending on the depth of the analysis |
| How many participants? | Any number; key members of a team who have a collective awareness of all aspects of a project |
| How many researchers? | 1 moderator1 note-taker |
| What do you need? | Flipchart or whiteboard and some markers.Question guide |
| | Draw four quadrants and the two named axes |
| | - Could be done online with a Miro |
| How to? | (Preparatory work: inform the participants about the issue and propose them to make personal research) |
| | Identify the most important stakeholders in the issue |
| | Assess the importance that each stakeholder attaches to the issue |
| | Assess the influence of each stakeholder on the issue |
| | Position the stakeholders on the identified quadrant and validate with participants |
| | Variables affecting stakeholders' relative importance and influence: |
| | Within and between formal organisations: |
| | Legal hierarchy (command & control, budget holders) |

- Authority of leadership (formal, informal, charisma, political, familial or cadre connections)
- Control of strategic resources
- Possession of specialist knowledge & skills
- Negotiating position (strength in relation to other stakeholders)
- For informal interest groups and primary stakeholders:
 - Social, economic and political status degree of organisation, consensus and leadership in the group
 - Degree of control of strategic resources
 - Informal influence through links with other stakeholders
 - Degree of dependence on other stakeholders
- Questions which can be used to analyse further:
 - Which problems, affecting which stakeholders, does the research seek to address or alleviate?
 - Whose needs, interests and expectations will be met most by the research?
 - Which stakeholder interests converge most closely with the research objectives?
 - Which stakeholders can have a negative influence on the research results? How can this be countered or mitigated? (adapted from Brouwer & Brouwers 2017⁶)

Advantages

- Help to identify situations where:
 - Significant awareness-raising is required to turn a highly-influential but low-interest stakeholder into an interest potential stakeholder
 - Significant capacity development is required to turn a stakeholder with high interest but low influence into a stronger potential stakeholder.
- Help to prevent potential misunderstandings about and/or opposition regarding a specific issue
- When used in a mixed group of stakeholders, support for implementation of solutions

Attention points

Influence and importance of stakeholders are rarely clear cut

Extra tips

- Better to conduct with heterogeneous group to allow for diversity
- Define a specific issue, that needs to have a controversial dimension
- Add other data sources to support the matrix (literature, individual interviews, ...)

To go further

- Brugha R, Varvasovszky Z. Stakeholder analysis: a review. Health policy and planning. 2000;15(3):239-46.
- NHS Improvement. Stakeholder analysis. 2021.
- Schmeer K. Stakeholder Analysis Guidelines. 1999. WHO.
- https://gamestorming.com/stakeholder-analysis/

Online demo

@KCE

- Piérart J, Leonard C, Chalon P, Daue F, Mertens R. "Stakeholder Involvement" dans les processus du KCE. Method. Bruxelles: Centre fédéral d'Expertise des Soins de Santé. 2012. KCE reports 174B. D/2012/10.273/10.
- Piérart J, Leonard C, Chalon P, Daue F, Mertens R. "Stakeholder Involvement" in de KCE werkprocessen. Brussels: Kenniscentrum. 2012. KCE reports 174A. D/2012/10.273/10.

A.

high importance low influence the "victims"

D.

low importance low influence the difference

D. low importance low influence the "bystanders"

C. low importance high influence the "irresponsible"

Figure 6 – Matrix for stakeholder identification

Level of influence

3.13 Stakeholder identification

| What is it? | This tool allows for a quick visualisation of actors in an issue and their interrelations. This tool could be used several times during a project as the roles of stakeholders may change over time, requiring an update of previous stakeholder analysis ⁶ . |
|-------------------|--|
| Objectives | - To identify actors when initiating a research |
| | - To review a situation with an established research project |
| When to use it? | Scoping phase: to identify potential interest groups and potential research questions |
| | Design phase: to identify the stakeholders to be involved for the recruitment |
| | Analysis phase: based on collected data, this could serve as a template to organise information in a meaningful way |
| | Dissemination phase: to identify those to be informed in priority and adapt the messages |
| How long? | - 1h |
| | 3h in the analysis phase as participants need to understand the collected data |
| How many | - No defined number of participants |
| participants? | - Diversity is an asset to ensure a large overview of the issue |
| | Pay attention that groups over 12 persons (6 online) are more difficult to manage |
| How many | - 1 moderator |
| researchers? | - 1 note-taker |
| What do you need? | - Whiteboard or wallpaper + sticky notes and markers |
| | - Could done online (i.e. Miro) |
| How to? | - Start by listing to all the stakeholders concerned by the issues |
| | Define a legend for the arrows, such as intermittent arrows for weak connections and thick arrows for strong connections. Arrows can point both ways. Choose different colours to signify different types of relationships. |
| | - Identify the relations between the stakeholders |
| | - Identify subgroups with common goals |
| | - Identify those at the centre of the issues and those at the periphery |
| Advantages | - Quick and easy to use |
| | - Provides a good overview |
| Attention points | - Homogeneous groups could reach saturation quickly |
| Extra tips | Combine it with a influence & power matrix to get more into the details |
| | - Include the collected data in a software of social network analysis |
| To go further | Boaz A, Hanney S, Borst R, O'Shea A, Kok M. How to engage stakeholders in research: design principles to support improvement. Health Res Policy Syst. 2018;16(1):60. |
| | Leventon J, Fleskens L, Claringbould H, Schwilch G, Hessel R. An applied methodology for stakeholder identification in transdisciplinary research. Sustain Sci. 2016;11(5):763-75. |

| | Schiller C, Winters M, Hanson HM, Ashe MC. A framework for stakeholder identification in concept mapping and health research: a novel process and its application to older adult mobility and the built environment. BMC Public Health. 2013;13:428. |
|-------------|--|
| Online demo | |
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| What is it? |
|------------------------|
| Objectives |
| Useful for? |
| When to use it? |
| How long? |
| How many participants? |
| How many researchers? |
| What do you need? |
| How to? |
| Advantages |
| Attention points |
| Extra tips |
| Online demo |
| To go further |
| @KCE |

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 - 10. Evaluation Toolbox. Problem Tree / Solution Tree Analysis [Web page].2010 [cited 2021/05/06]. Available from: http://evaluationtoolbox.net.au/index.php?option=com_content&view=article&id=28&Itemid=134
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Colophon

Title: Animation techniques for better patient involvement

Authors: Marie Dauvrin, Laurence Kohn, Irina Cleemput

At the request of: KCE Management

Disclaimer: This document is a compilation of animation techniques retrieved from

several resource collections over patient involvement. The literature included in these repositories is not always peer-reviewed or externally validated. KCE synthesized the evidence in short time frames to respond to the need of providing KCE researchers with animation techniques relevant

in the context of the KCE project.

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