

APPENDIX 5: MULTI-ACT Patient Engagement Methods

Below are listed and briefly described engagement methods recommended by the Multi-Act.

Focus Group	<p>Focus Group is a qualitative method which is used to determine the preferences of people or to evaluate strategies and concepts. The method has originally been designed for market research. Focus group is undoubtedly the most widespread technique of engagement. It is rooted in qualitative studies, where it is a standard way of gathering patients' input and learning about their views and experiences. Its scope of application has widened in recent years, with the method being used for decision-making and guidelines formulation (Doria <i>et al.</i>, 2018), not without some criticism regarding insufficient separation of these two functions.</p> <p>Participants are selected according to certain common characteristics that relate to the research topic and are grouped into 8-10 people.</p> <p>It can be conducted face to face or in virtual digital space. The method is often used to generate or evaluate hypotheses and ideas in conjunction with a quantitative method, or as a primary data-collection method.</p> <p>Example: Selected patients and stakeholders are invited to a meeting to discuss about a topic.</p>
Democs	<p>It is both a card game and a policy-exploration tool that enables small groups of people to engage with complex public policy issues. It aims to help people find out about a topic, express their views, seek common ground with other participants, and state their preferred policy position.</p> <p>There are already a number of Democs kits on different issues which can be bought or downloaded for free from New Economics Foundation (NEF) and Play Decide.</p> <p>Example: Patients are provided with discussion cards that help them to express their views on a topic, to seek common ground with the other participants, and to express their preferences.</p>

World Café	<p>It is a method for engaging groups, both within organisations and in the public sphere. World Cafés are based on seven design principles and a simple method. World Cafés should offer an antidote to the fast-paced fragmentation and lack of connection in today's world. It is founded on the assumption that people have the capacity to work together, no matter who they are. Research indicated that World Café was not a popular method of engaging patients in the healthcare context, although some examples emerged. This may be in part due to the open-ended feature of the method. It is suitable for generating and sharing ideas, but does not guarantee a structured result, and does not support structured decision-making. (Engage2020, 2015)</p> <p>Example: A selected group of patients and stakeholders are invited to share their vision and position about a topic in a friendly space, and are encouraged to provide contribution to the debate.</p>
Community Advisory Board	<p>The Community Advisory Board (CAB) is a working group where patient advocates leaders from all world regions, work together to improve outcomes of patients covering patient information, research priorities, access to treatment and capacity building in the patients' community (CML Advocates Network, 2018). The CAB method is used in leukaemia communities and by the HIV movement.</p> <p>Example: Patient advocate leaders are invited as member of the working Group to work on a topics.</p>
Delphi	<p>The Delphi method is a multiple iteration survey method that enables anonymous, systematic refinement of expert opinion with the aim of arriving at a combined or consensual position. Its purpose is to generate discussion and enable a judgement on a specified topic to be made so that policy decisions can be taken which can claim to represent a given group's wants and views. Along with modified Delphi Method, it emerged as the second most popular patient engagement technique after Focus Group. Initially designed for panels of experts to arrive at decisions without influencing one another, it is increasingly used for including patients, either forming their own panel, or together with experts and other stakeholders (e.g. community, healthcare professionals) (Hall <i>et al.</i>, 2018). Delphi can be applied online and it often is. Delphi Method appears to be a popular tool for prioritisation of core-outcomes in patient-centred guidelines (Humphrey-Murto and de Wit, 2019), often in multi-stakeholder initiatives.</p> <p>Example: anonymous patients answer to multiple surveys to express their opinion about an approach defined by experts.</p>

Consensus Conference	<p>The purpose of this method is to enrich and expand a debate on a socially controversial topic. A group of citizens gather, set the agenda and the basis for assessment within a problem area. In the medical field, consensus conferences gathered practitioners and experts to build a consensus on either health knowledge (e.g. diagnostic criteria) or practices (e.g. best practices, treatment protocols). The format of these consensus conferences differs from event to event and cannot always be equated with the Consensus Conference engagement method, which has wider application. This literature review found papers describing engagement of patients using the consensus conference method in the course of research with the view of formulating guidelines or core outcomes.</p> <p>Example: A series of public events are organized to gather patients’ opinions about a topic and may result in a position paper.</p>
Citizens Hearing	<p>“The purpose of a citizens hearing is to inform and create discussion among citizens. The method uses brainstorming, dialogue, prioritization, reasoning and voting. Through dialogue and without interference of either experts or politicians, the citizens formulate their own suggestions and ideas (as to how a political (technological) problem can be dealt with) and present them to politicians” (Engage2020, 2015). Some examples show how citizen hearing has been used to investigate the preferences of patients with respect to specific issues such as for example the use of health data and the status of health rights. This method enhanced the understanding and awareness of the barriers and achieving positive solutions to help overcome them; and seek commitment on a joint plan for monitoring and acting on the topics.</p> <p>Example: Patients brainstorming, dialogue, reason and voting about a topic, without interference from any experts.</p>
Serious Gaming	<p>“The primary objective of ‘serious games’ or ‘applied games’ is to train and/or educate the user. These games serve as tools for acquiring complex knowledge in fields such as health care, education, engineering, city planning, emergency management, etc. Some serious games simulate real-life events and/or processes, thus providing the user with a problem-solving training environment. Furthermore, ‘serious games’ can be used in order to develop innovative products and services.” (Engage2020, 2015)</p> <p>Example: Patients are trained with an ICT game that presents the problem in a simple and fashionable way. The game is structured to provide patients with a training environment for problem-solving.</p>

Research Studios Method	<p>This method allows researchers to work closely with community members as they design studies. In 2009, the Meharry-Vanderbilt Community-Engaged Research Core began testing new approaches for community engagement (Cunningham-Erves <i>et al.</i>, 2020), which led to the development of the Community Engagement Studio (CE Studio). This structured program facilitates project-specific input from community and patient stakeholders to enhance research design, implementation, and dissemination. Developers used a team approach to recruit and train stakeholders, prepare researchers to engage with stakeholders, and facilitate an in-person meeting with both. Literature reported that input from stakeholders was valuable and that the CE Studio helped determine project feasibility and enhanced research design and implementation (Joosten <i>et al.</i>, 2015).</p>
Scenario Workshops	<p>An instrument for participatory planning, it is based on dialogue and collaboration between local citizens, stakeholders, experts and policy makers. The method aims to stir dialogue, provide the opportunity for exchanging experience and knowledge, and facilitate consensus on proposed solutions among. It is a “two-days meeting involving 25-30 local multi-stakeholder representatives to assess different solutions to a specific problem. Before the workshop, a set of scenarios is developed and used as visions and inspiration at the scenario workshop.” (Engage2020, 2015)</p> <p>Example: A Scenario Workshop is organized to discuss in a multi-stakeholder group on a specific R&I problem. The assessment of the different solutions proposed by patients and stakeholders results in defined and agreed actions to solve the problem. Patients comments on the scenario based on their experiential knowledge.</p>
World Wide Views	<p>The method is designed to closing the gap between citizens and policy makers in the context of global policy-making. Citizens at multiple sites debate the same questions on the same day. They are given materials before and during the day and then vote to choose pre-defined questions. “The votes are collected and reported online for comparison. It is possible to compare the votes across countries, continents, gender, age and other criteria. The results are analysed and presented to policy-makers.” (Engage2020, 2015)</p> <p>Example: A World-Wide Views is organized to gather patients’ votes on a set of predefined research questions and policy-makers to design R&I and healthcare policies use results.</p>
Voting Conference	<p>Used in small settings and with diverse target groups, it is an approach similar to World-Wide Views. E-conference (temporary online forum on a specific topic) can be used as tool (Engage2020, 2015).</p> <p>Example: A Voting Conference is organized to collect patients’ votes on a set of predefined research questions and results are integrated in R&I activities.</p>

Deliberative Polling®	Developed by James Fishkin, the public consultation method which combines deliberation in small group with scientific random sampling. It informs public policy. (Engage2020, 2015)
Deliberative online forum	Web-based (in online forums) discussions between informed individuals about issues which concern them, leading to some form of consensus and collective decision (Engage2020, 2015).
Deliberative Mapping	Involving both specialists and members of the public, it combines varied approaches to assess how participants rate different policy options against a set of defined criteria. The method allows substantial involvement of public participants (Engage2020, 2015).
Deliberative Workshops	<p>Events with a focus on in-depth informed discussions on complex or controversial issues to inform policy and regulation, exchange opinions or raise awareness. This method has also been used to develop research agendas and objectives (Engage2020, 2015).</p> <p>Example: Patients are engaged in deliberative surveys, small group discussions, online forums, dialogue events, etc. to express their opinions on specific R&I's questions and issues and the results are used for deliberating on specific R&I policies. Patients can also rate different policy options against a set of defined criteria.</p>

Literature

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