

Patient centricity – Co-Creation puts the patient at the heart of medical development

In a 2015 white paper: *The Future of Clinical Trials: How Bringing Patients to the Centre can Cut Costs and Deliver Better Outcomes*, Anne Beal makes the important distinction between patient centricity and patient engagement.

Beal considers that patient centricity is about focusing on the patient needs, where as patient engagement is about the *"... process by which patients are brought in and are asked to help direct and shape activities like research ..."* Put simply, if our healthcare efforts are not patient centric then what are we doing? To quote Beal *"... it would be professionally embarrassing not to have a specific statement on patient centricity, because it should be how we do our business."*

Putting this into a patient reported outcome (PRO) context, the outcome must be patient centric, in other words it must be related to the needs etc. of the patient but, how do we achieve this? The how? The answer is through **"patient engagement"**.

With the US Food and Drug Administration (FDA) call for patient-focused drug development and the National Institute for Health Research (NIHR) as well as the National Research Ethics Service (NRES) requesting grant applicants to provide evidence of their plans for patient and public involvement (PPI) in the research, patient engagement is very much on the agenda.

What is patient engagement?

According to Beal, patient engagement is about the *"... process by which patients are brought in and are asked to help direct and shape activities like research .."*

Establishing content validity of a PRO to ensure it measures the concept(s) of interest and that the items and domains are both relevant, traditionally focuses on a combination of a review of the relevant literature and input from clinicians and patient engagement through in-depth interviews, focus groups and online concept elicitation surveys.

Although a powerful approach for identifying issue relevant to the patient, the emphasis remains very much based around patients responding to the issues previously identified by the researcher as relevant and which form the basis of the interview discussion guide as an *aide memoire*. Pretty much the same can be said for using focus groups for generating valid PRO content.

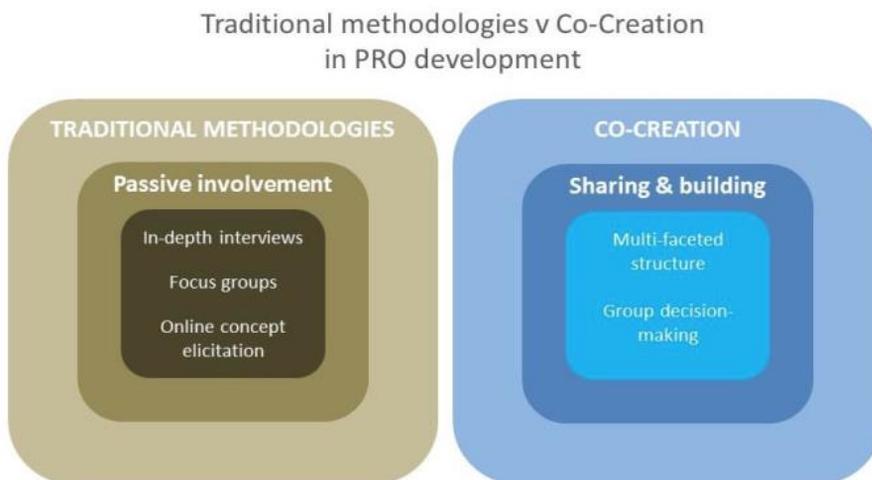
Although contributing to the research process the patient is passively involved by virtue of responding to the researcher's frame of reference rather than the patient's. Is this really "Putting the patient at the heart of PRO development?"

An alternative approach is co-creation, which ensures the patient is at the heart of the process whether it is PRO development or designing a patient-centric clinical trial. Co-creation is not new to brand development with companies such as Coca-Cola and Microsoft using the approach to tap into the insights of their customers.

What is Co-creation?

The term co-creation is used fairly indiscriminately and with a lack of conceptual clarity. It should however, not be confused with concepts such as 'crowdsourcing' or 'user generated content'.

Co-creation is creative as a form of collaborative creativity.' It's a rich mix drawing on a combination of knowledge, and group decision-making. It's the process of involving the client/customer/patient in the creation of meaning and value.



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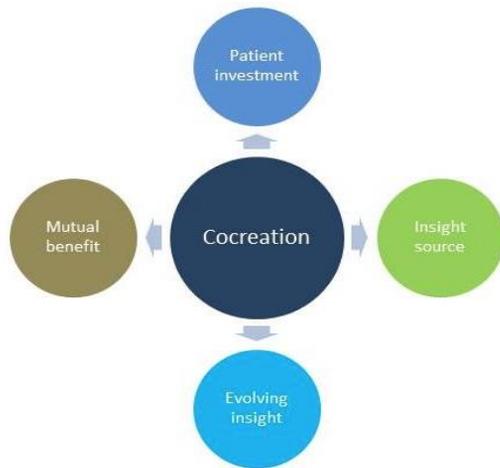
Developing a PRO or patient-centric clinical trial through co-creation brings patients and key stakeholders (e.g. researchers, clinicians, pharmaceutical advisors) together who are tasked to collaboratively generate ideas and concepts through a range of stimulating activities.

Although these techniques and methodologies include a synthesis of existing information as a precursor to the qualitative phase of content identification and generation, one important aspect is the methodology differs from the traditional use of in-depth interviews and focus groups, which is that concept identification and content generation is a collaborative process.

The emphasis is very much on interaction between patients and stakeholders and the sharing and building on ideas. Importantly however, it is for the patient to own the brief and to show what they think, feel and experience, from which triggers, trends and actionable insight can be identified.

The benefits of co-creation

Within the context of deriving PRO content, there are a variety of emerging qualitative methodologies that go beyond our existing reliance of in-depth interviews and focus groups. In the case of co-creation these include:



- **Outcomes are relevant** because stake holders are directly involved
- The complete co-creation process ensures **broad support** from all stakeholders, since they are directly involved
- Collaboration and direct dialogue is **highly inspiring**
- Co-creative processes have a **strong positive impact** on the quality of the result

3 Types of Co-creation Methods

Described below are the key types of co-creation research methods together with an overview of some of their main strengths and weaknesses.

1. Online Communities or Panels

Using a pre-selected 'community' or 'panel' of patients/carers, online software output and feedback can be shared, controlled and managed. This enables an interactive and iterative approach to the identification and development of ideas and concepts.

Strengths

- Achieve a continuous dialogue with the community or panel
- Get a comprehensive range of responses from a fairly large number of participants
- Communities can work with each other to get more and better ideas

Weaknesses

- Participation and ongoing dialogue need to be highly incentivised
- Limitations of being online verses face to face
- May require considerable investment
- Tendency for breakoffs and other In home distractions

2. Co-creations workshops

Scale developers invite a selection of patients, carers and other key stakeholders to participate in an innovation workshop, providing at the moment insight to guide further ideas and thinking.

Strengths

- Interactions between participants experienced first hand
- Ideas and concepts can be challenged/developed quickly
- Ideas/concepts based on reality

Weaknesses

- Participants might be overwhelmed by the experience
- Challenges to participant thinking can be difficult
- Participants may tell you what they think you want to hear
- Facilitator limited in developing strong rapport with participants
- Certain participants may dominate the group

3. Small groups

While similar to focus groups, the groups are smaller enabling a more focused dialogue.

Strengths

- Enables closer interaction and bouncing of ideas off one another
- Enhances dialogue between participants
- Greater participant engagement
- Reduces the normal limitations of a focus group

Weaknesses

- Potential for dominant individuals to bias the group
- Limited ability for facilitator to develop strong rapport
- Need to co-create together to mitigate the usual limitations of focus groups

Choosing the methodology

While any of the three methods described will provide insights into the development of the outcome measure and trial design, it must be borne in mind that some methods are more suited than others to the specific challenges set. For example, getting topline clues, online communities will suffice. However, understanding participants' sub-conscious, needs and drivers and identifying and developing concepts will require a methodology that enables the facilitator to:

- Create deep rapport
- Dig deep
- Utilise the power of body language
- Apply techniques to enhance participants spontaneous thinking

Summary

With the increasing need for medical development companies to focus on the patient journey from the patient's perspective, this paper provides a brief summary of three co-creation methodologies together with an overview of their strengths and weaknesses as innovative approach to patient-centred drug development including trial design and outcome measure development. Each methods differs in the depth and quality of insight gained, ranging from topline clues to understanding participant needs and drivers. Therefore, the method selected must be appropriate for the challenges set.

About Health Outcomes Insights

Health Outcomes Insights is an independent research consultancy serving academia, life science researchers, healthcare agencies and the pharmaceutical industry, get targeted answers to patient behaviour, experience and health outcomes across a range of conditions and diseases – with particular expertise in diabetes.

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