

CO-CREATING CONTENT WITH PATIENTS: A BEST PRACTICE GUIDE FOR THE LIFE SCIENCES INDUSTRY

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Emma Bishop, Head of Content, Cognitant



COGNITANT

Whitepaper

WHAT IS CO-CREATION?

In recent times, the life sciences industry has been trying to find better ways to listen to the patient and carer voice. Patient engagement and support programmes are changing, and the concept of co-creation is becoming increasingly important.

It makes sense to listen to the patient and their needs when it comes to developing medicines and services. New design approaches such as experience-based co-design (EBCD) and organisations such as the Social Care Institute for Excellence (SCIE) have introduced quality improvement approaches that help to enhance the patient experience of care. However, while most within the industry are on board with the concept of patient-centricity, regulation and lack of clarity around it can make co-creation feel like a difficult task.

WHY CO-CREATE WITH PATIENTS?

Involving patients in the creation and development of your content can help you consider their long-term needs and how to optimise support programmes.

It has been shown to support people, products and companies through:

- improving adherence to positive health behaviours and outcomes
- generating real impact with high levels of engagement
- aiding the personalisation of content, increasing patient satisfaction and trust

Establishing co-creation means bringing patients in early and involving them every step of the way – whether it is at R&D stage for the creation of lay summaries, creating a new drug or treatment, or co-developing education and support materials.

Creating solutions that patients are invested in helps to build advocates for your company or project, ultimately scaling your ability for impact through patient partnerships.

Co-creation is about collaborating with patients and caregivers to enable you to develop an in-depth understanding of the patient experience. It's about striving to hear what patients are interested in, what they want and how they want to receive health information.

THE COGNITANT PROCESS FOR CO-CREATION

At Cognitant, we specialise in creating educational resources and support tools for patients. We apply a user-centred design to projects to better understand user needs. This helps us to identify insights and opportunities to design solutions that really work for patients. Our iterative design process means we are able to bring together the relevant stakeholders at the right time and co-create with patients to develop solutions that drive positive outcomes.



1. DISCOVER

We identify pain points, obstacles and challenges along the current patient journey. This provides us with an opportunity to innovate – we work to fill gaps, focusing on who could benefit most from the proposed technology, validating unmet learning needs, and analysing key trends that could inform our curriculum.

Map the patient journey

We bring in patients (who may be patient experts), patient advisory groups and healthcare professionals from the relevant therapy area to help us map the journey from different perspectives, and ideally from home to home.

Carry out patient focus groups

We ensure these are well facilitated with a clear agenda, working with patients to explore a variety of different issues, to test solutions, to explore the group’s perspective and to generate ideas.

Consider barriers to learning

Learn about any barriers that prevent patients from understanding their condition or health behaviours. This could be related to their condition or the region that the content will be released in. For example, should content be developed in multiple languages, or tailored to different cultures? This background research can aid the creation of widely useful programmes, reduce health inequities and drive positive change.



2. DEFINE

We continue to work with patients and healthcare professionals during this stage, to bring both sides together and to review different elements of the design. This helps us shape the technology and validate what topics provide the most value.

Start to discuss potential solutions

At this stage, we start to think about if and how technology could be used to solve the issues highlighted in the discovery phase.

We begin to put together a curriculum – answering such questions as: what is the *right* information for the patient? What are the priority topics? Where does this fit in the clinical pathway, so we can ensure it’s delivered at the *right* time?

We also gather consensus on patient-preferred styles, approach and language, in order to create audience-appropriate content. We probe further to build true insights into the patient experience, including: what the individual patients thought, what they do, their wants and needs, along with their fears or frustrations, their influencers and environment.

Review process with stakeholders

We bring stakeholders into this process to review different elements of the design. This ensures we have all perspectives to get the best possible outcome.



3. DEVELOP

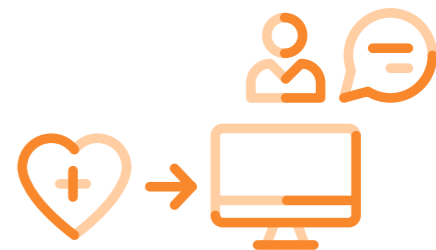
We use an iterative design process, based on regular feedback. We facilitate this process, obtaining feedback from patients, patient charities and stakeholders to produce a script and a storyboard.

Review prototype and test

A short prototype is then created, and we can start beta testing. By collating feedback, we can continually improve the service based on end-user acceptability, satisfaction and experience.

Full build of solution

We then build the agreed solution, taking into account everything we’ve learnt during the review and test stage.



4. DELIVER/ EVALUATE

Once the solution has been released, we conduct more testing and evaluate the impact by collecting patient feedback on full-programme acceptance, satisfaction, experience, and (where possible) outcomes. The process is adaptive – we implement any required changes in response to the feedback, taking all information from the discover, define and develop stages into account.

GETTING THE BEST RESULTS FOR PATIENTS

The following case studies provide examples of where we have applied our co-creation approach.

CASE STUDY 1 Helping patients understand chronic kidney disease



Royal Berkshire
NHS Foundation Trust

Cognitant and nephrologists at the Royal Berkshire NHS Trust worked with people diagnosed with chronic kidney disease (CKD) to help them understand the details of their condition and how to look after their kidney health. The initial objective was to evaluate how patients understand and want to consume health information about their CKD.

Why co-creation?

43% of people lack the literacy skills, whilst 61% lack the numeracy skills to understand typical health information in England. Low health literacy is associated with greater difficulty in managing chronic illness, greater use of medical services, lower levels of health, and higher rates of mortality in older people, vs higher rates of health literacy. A co-creation approach was used to evaluate how patients understand and want to consume health information about CKD, including a method to evaluate whether patients preferred written or digital information.

How we solved it

By getting patients involved from initiation, we were able to discover that the majority of patients preferred immersive, interactive or animated health information. The digital information we created could be accessed by patients via 'Healthinote', Cognitant's health information platform, using a QR code or hyperlink, and viewed on their mobile, tablet or using Google Cardboard. Patients cited that the information was easier to get to grips with, understand and manage their condition through visual explanations as they were able to learn at their own pace.

*"I like having written information but watching it on a phone made it all feel a bit **easier to get to grips with**" Patient*

"This app provides high tech, high quality information making it more accessible to patients that struggle with literacy" GP

CASE STUDY 2

Working with people with diabetes in Colombia



With the number of new cases of diabetes in Colombia rising, Cognitant initiated a project to help improve patient self-management. The aim was to help people with type 1 or 2 diabetes experience better clinical outcomes, including quality of life, by empowering them with a greater understanding of their condition and medication. The initial phase focused on helping at-risk patients prevent hypoglycaemia.

Why co-creation?

Current delivery of health information was reported by patients to be insufficient, inaccessible, difficult to understand, and sometimes unreliable. A co-creation approach ensured that the programme included the right topics, that the information was simple and delivered in the preferred visual format to maximise engagement and impact.

The 'define' phase of the co-creation project helped confirm unmet patient needs – allowing us to gain close insights into each individual patient's thoughts, their wants and needs, fears or frustrations, their influencers and environment. During the 'delivery' phase, we conducted online focus groups and web surveys, testing three different digital prototypes to explain what hypoglycaemia was and the basics of glucose dynamics. Both phases provided truly valuable insights into real-life patient experiences, such as their preferences for consuming health information, their everyday personal struggles with diabetes, barriers to learning and health behaviour adoption, and how they wanted to receive support.

The result

We were able to identify the best and most impactful approach in terms of patient engagement and outcome. Participant feedback was extremely positive, with one patient reporting that the programme had helped them to identify that they had been experiencing hypoglycaemia, having previously mistaken events for perimenopausal symptoms – meaning the pilot alone had delivered immediate value.

"I have had diabetes since I was 5 years old and I have seen everything from books, guides, brochures, group workshops, medical visits. All that is boring and you don't pay attention, the videos are very friendly and help to gain interest, they involve you with your sight and hearing and educate you better" **Patient (translated from Spanish)**

OUR TOP TIPS FOR CO-CREATION GROUPS

- 1 **Plan carefully** – it's important to create the right environment for everyone in the group to share their experiences. Some people might be nervous to share personal information. Also consider whether healthcare professionals and patients should be together in the same group.
- 2 **Have a clear agenda** – your approved agenda and any relevant pre-reading material (pdfs) should be sent to eligible participants in advance via email. This will put people at ease before the day starts as they will know what to expect – though make sure you don't overload them with information.
- 3 **Make sure that people have an equal say in the group** – choose your chair carefully as some patients may not feel confident to speak up in a group of strangers. You could consider asking a patient to chair the session to put other people at ease.
- 4 **Be mindful of patients' needs** – ensure the venue and timings are suitable for the demographic of those in the focus group. It's important to consider that some may suffer from fatigue, be on strong medication or have a handicap. Think about whether a virtual platform is more appropriate and accessible. Virtual whiteboard tools such as Miro Board or Mural are a useful way of capturing what is discussed on the day.
- 5 **Consider health literacy** – make sure the language you use throughout the day is easy to understand. For example, instead of using the word 'acute' try saying 'lasting a short time, but often causes a serious problem'. Avoid complex medical jargon and abbreviations, and keep it relevant to the patient's experience. Consider using visual aids.
- 6 **Consider language preferences** – aim to conduct the co-creation process in the person's native language and provide supporting documents in translated versions if necessary.
- 7 **Keep people involved throughout the whole process** – don't forget to share the findings of your focus group with people. Following up with participants once you have some results will make them feel engaged and more likely to want to take part in additional groups with you.
- 8 **Think about how you can generate creative thinking** – try to allow people to look at an opportunity with fresh eyes. Enquire, probe and question - have a two-way conversation with patients and other participants in the process. This will allow you to generate new ideas that you might not have thought about.
- 9 **Be prepared for an iterative process** – you need to adopt a test and lead approach for continuous improvement. It might be that your user testing highlights further issues or obstacles along the way.

Complying with industry process

Our co-creation method always complies with ABPI Code of Practice, as required. For example:*

- Prescription-only medicines (POMs) must never be advertised to the public
- Information must be factual and balanced, and must not be misleading in terms of efficacy or safety
- Content must not encourage people to ask their healthcare professional to prescribe a specific POM
- Patients must be encouraged to consult their healthcare provider for personal medical advice and information

*Examples only, not an exhaustive list.

WHAT TO WATCH OUT FOR

- **Patients need to be reimbursed for their time and effort** – don't forget to include this in your initial budgeting for the project
- **Set up contracts ahead of time** – each healthcare professional and participant needs to be contracted individually, so leave yourself enough time to do this prior to running the group
- **Co-creation is different to advisory boards** – co-creation is regulated in a specific way with its own set of compliance rules, which must be recognised. Don't forget to acknowledge patients in their capacity as co-creator rather than advisory board capacity by recognising them in declaration statements
- **Include patients in recognition statements** to ensure people are recognised for their time and efforts

“Co-creation takes some careful consideration and planning, particularly in terms of compliance and certain limitations. However, it enables input from various stakeholders at the same time allowing cross-pollination of ideas, ultimately allowing for better engagement – from both patients and healthcare professionals” Medical Affairs Advisor, Pharma

HOW TO GET STARTED

Our co-creation approach is mindful of the rules and regulations that you have to comply with. Co-creation isn't difficult if you know the right methods to use and have the expertise to go about it. Hopefully our top tips can help you think about what's possible, in order to get the best possible outcome for the patient. Ultimately, it's about treating them as partners throughout the entire process and not simply a focus group used for feedback. It can support you and the patient to get the best result for their condition.

At Cognitant, you can trust that co-creation with your patients will be done professionally. We understand the market and have key relationships with contacts in the NHS, patient charities and leading experts across the health and care sector. This means we are uniquely placed to hold focus groups that get the right people around the table and design solutions that are tested in the market. Our co-creation method not only unearths unmet needs for specific patient groups, it allows us to discover which methods work best for the end-user and how to deliver engaging and meaningful programmes.

To find out more about what we do, contact hello@cognitant.com or visit www.cognitant.com

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hello@cognitant.com
www.cognitant.com