CDS Innovation Collaborative

Involving End-Users in Co-Design of Patient-Centered Clinical Decision Support

This chartbook provides an overview of key takeaways from Trust and Patient-Centeredness Workgroup: Methods for Involving End-Users in PC CDS Co-Design, developed by the Agency for Healthcare Research and Quality's Clinical Decision Support Innovation Collaborative (CDSiC). It is designed to help developers of clinical decision support identify and use methods of co-design to advance patient-centered clinical decision support.

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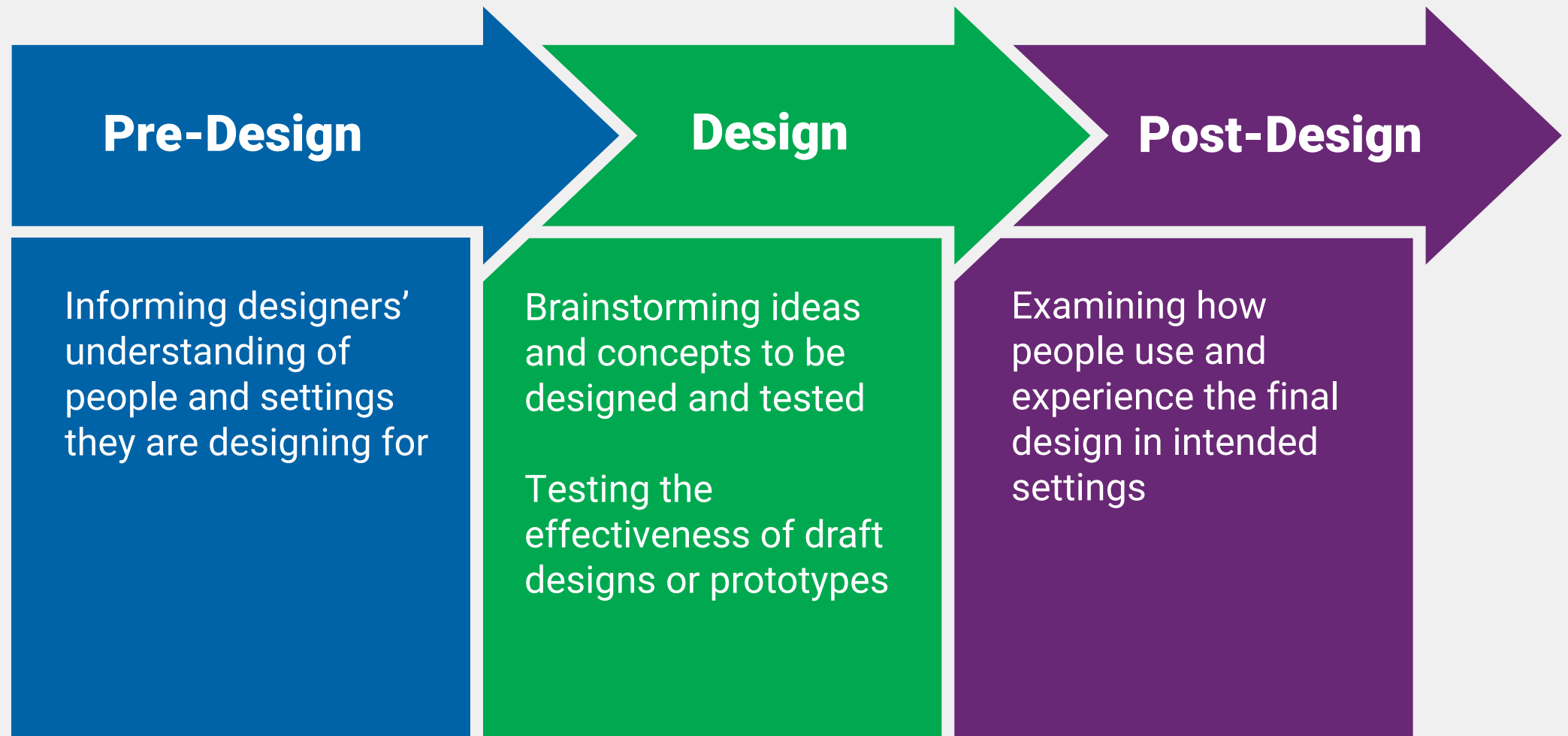# End-User Involvement Essential to Development of Patient-Centered Clinical Decision Support

Clinical decision support (CDS) development has historically been spearheaded by health systems leaders, electronic health record (EHR) developers, and informaticians.[1] Unless CDS developers prioritize end-user needs and preferences or invite end-user input during design, patient-centered clinical decision support (PC CDS) may not align with clinician workflows or patient lifeflows. Co-design may help to prevent such unintended consequences by:

- Deepening developers' understanding of the needs and challenges end-users face in their roles.[2,3,4]

- Inviting perspectives from other key stakeholders so that PC CDS design accounts for feasibility or other context considerations.[5]

- Integrating different forms of knowledge and/or vantage points that each design partner can bring.[6]

End-User Involvement Is Essential to Development of Patient-Centered Clinical Decision Support

Generally, co-design proceeds in a sequence of Pre-design, Design, and Post-design phases.[7,8] Co-design methods, described next, can serve different purposes at distinct points in the process. For example, developers may want to understand the context in which end-users will use PC CDS during Pre-design, while during the Design phase, developers may be observing end-users' reactions to a prototype. Post-design, developers are focused on monitoring to determine further adaptations.

Pre-Design

Informing designers' understanding of people and settings they are designing for

Design

Brainstorming ideas and concepts to be designed and tested

Testing the effectiveness of draft designs or prototypes

Post-Design

Examining how people use and experience the final design in intended settings

There Are Many Ways To Involve End-Users

The report identifies and describes six overarching methods that can be used individually or synergistically to involve patients, clinicians, and other stakeholders in PC CDS co-design. The table at right provides an overview of these methods. Please note that co-design methods differ relative to parameters such as intensity and reach. For example, surveys are considered a low-intensity form of involvement as they require a limited commitment of time, resources, or information sharing. Thus, they can have a broad reach, in part because they pose few barriers to involvement. On the other end of the spectrum, consultive groups require deeper, repeat, or sustained forms of involvement and may have narrower reach as they require greater investments from co-design partners.

Method	Example Activities
Consultative Groups	Convening single or multi-stakeholder groups to inform developers' choices such as: • Steering Committees • Advisory Boards
Surveys	• Soliciting input via online or paper formats on end-users' characteristics (e.g., age, education level) • Goals, needs, preferences, and values • Challenges to be addressed through PC CDS • Contexts for which design may need to be tailored
Focus Groups	Holding planned, facilitated discussions with end-users to solicit quick, simultaneous input
Empathy Interviews	Conducting interviews with unstructured or semi-structured formats and open-ended questions to elicit stories about end-users' experiences
Prototypes	• Brainstorming to prompt creative thinking and organize ideas • Mental modeling activities to explain end-users' understanding of how PC CDS-relevant processes work • Co-creation and iterative testing of a mockup of the product design
Usability Tests	• Interviews designed to solicit feedback on prototype usability • User diaries that allow end-users to document their experiences and reactions to a prototype • Developer/researcher-observed simulated or real-world interactions between end-users and prototypes

Providing Structure for Input Through Consultative Groups

Consultative groups such as steering committees or advisory boards provide a structure and schedule for eliciting targeted input, as well as sustained involvement in governance or leadership. This includes PC CDS co-design partners, such as patients, caregivers, and clinicians. These groups can have different goals and objectives (e.g., providing feedback on the design itself vs. on the co-design process) as well as forms (e.g., working groups, steering committees, communities of practice, etc).[9,10,11]

Potential Uses	Consultative groups can influence different kinds of decisions made throughout the co-design process: those solely focused on PC CDS design; or those broadly focused on the co-design process in the Pre-design and Design phases.
Real-World Examples	• A group of mothers with children (e.g., a single-stakeholder group of patients/caregivers) who have complex medical needs that consults on co-design activities, such as providing feedback on planned features and functions of PC CDS. [7] • A multi-stakeholder group of patients, clinicians, researchers, and delivery system leaders that engage at various points of the co-design process, such as evidence synthesis and idea generation during Design.[9]

Gathering Input from a Large Audience

Surveys can provide insight into (1) which information or features end-users require to effectively use PC CDS, and (2) how end-users would rank, prioritize, or interact with these PC CDS features.

Potential Uses	During Pre-design, surveys can help developers understand how PC CDS will be used.[12] Surveys can also be used during Design phases to determine which features should be included in PC CDS and to solicit data on the effectiveness.[13,14]

Real-World Examples	• A survey during Pre-design distributed to patients to help researchers understand the information needs of target users and their preferences to inform the CDS.[15] • During Design, surveys to clinicians soliciting feedback on PC CDS design elements such as layout, visuals, and amount of content.[13]

Getting Quick, Simultaneous Input from Multiple End-Users

Focus groups are planned, facilitated discussions inviting input on a pre-determined topic or product.[21] They highlight similarities and differences across end-users' needs, values, and perceptions.[22] Depending on the nature of feedback sought, focus groups can be conducted virtually or in person.

Potential Uses	Focus groups can be used across design phases to understand how PC CDS might be used, and also later in the process for insight on how end-users interact with PC CDS and which elements are most effective
Real-World Examples	• In Pre-design, using a focus group with clinicians to help explore challenges clinicians face in recommending treatment options. [18] • During Design, using focus groups to support the refinement of prototypes asking patients and clinicians to provide feedback on features, appearance, and suggested revisions.[4]

Helping Developers Empathize with End-Users

Empathy interviews help developers better understand the end-users for whom they are designing PC CDS, as well as the needs, objectives, and challenges that will dictate how clinicians or patients ultimately use PC CDS.[19]

Potential Uses	During Pre-design, empathy interviews help developers gather insight into how end-users interact with their environment or encounter problems that PC CDS is designed to solve. Empathy interviewing can also help developers transition from Pre-design into Design phases
Real-World Examples	• Job to be Done (JTBD) interviews with patients to elicit personal stories to solicit the root cause of problems or needs. For instance, end-users may not specifically need an app or an intelligent computerized system, but rather PC CDS that does the "job" of generating recommendations presented in digestible formats[20] • Researchers using empathy interviews with clinicians to understand clinician prescribing behaviors and the high rates of clinician override for drug-drug interaction alerts prior to redesigning CDS[21]

Creating Low-Resolution Mockups for Early Input

Prototyping is the process by which generated ideas are translated into low-resolution mockups or representations. Until a product is developed enough to take its final form, low-resolution prototypes can be used to solicit early input from end-users.

Potential Uses	Prototyping begins during Design and can be done through various activities to generate, organize, and vote on ideas; these ideas get translated into the design during prototype building activities
Real-World Examples	• Holding a series of prototyping workshops with end-user clinicians who brainstorm potential tools and solutions to inform the development of two model-of-care prototypes[22] • Developers of a shared decision-making tool using card sorting during prototype development, asking groups of patients and clinicians to sort cards into categories. After each group presents its model for categorizing the cards, end-users vote on the model they felt most accurately reflects patient experiences using dot stickers[23]

Assessing Effectiveness by Observing End-Users' Interaction with a Prototype

Usability testing methods involve asking about, or directly observing, end-users' interactions with a prototype to assess its effectiveness in meeting their needs. This includes qualitative interview methods to solicit end-users' verbal feedback about a prototype, as well as observation and monitoring as end-users naturally interact with the prototype to assess how or whether a prototype is effective.[24]

Potential Uses	To solicit qualitative feedback on the usability of a protype, directing end-users to test prototypes on their own and document their experience, or conducting direct observation of interactions between end-users and prototypes
Real-World Examples	• Patients testing the usability of a self-management app to describe what worked well for them and where they perceived areas for improvement to app developers • In the design of CDS for the management of fluids, electrolytes, and nutrition for critically ill pediatric patients, researchers observe and document clinicians' usual workflow while performing team rounds with an actual patient under observation[3]

Seven Steps for Successful Co-Design

Taking the following steps can help design team members and end-user partners successfully engage in co-design activities.

1. Communicate clearly about expectations and roles/ responsibilities.[25]

2. Demonstrate empathy and inclusivity.

3. Develop methods for bidirectional communications.[26]

4. Invite and integrate different types of end-user contributions.[27]

5. Negotiate and resolve conflicts proactively and collaboratively.

6. Establish an infrastructure for end-users to easily and equitably engage.[6]

7. Provide compensation for end-users.[27, 28]

Learn More
Read the full report, **Trust and Patient-Centeredness Workgroup: Methods for Involving End-Users in PC CDS Co-Design** for additional details on the features and benefits of each method, as well as key considerations when implementing co-design principles. The report presents a series of prompts that developers can consider when choosing methods that best meet their information needs and navigate their constraints throughout co-design.

About AHRQ CDSiC
The AHRQ Clinical Decision Support Innovation Collaborative (CDSiC) is a community of diverse stakeholders at the forefront of using technology to better support care teams, patients, and caregivers. The CDSiC is working toward healthcare decisions driven by both patient-centered and patient-specific information that align with patient needs, preferences, and values. Learn more at **https://cdsic.ahrq.gov/**.

Endnotes

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