

## PCORnet Engagement Definitions

**Note: These are PCORnet-specific definitions for use in PCORnet operations.**

Term	Current PCORnet Glossary Definition	Link	Revised Definitions with Committee and Workgroup Recommendation
<b>Patient (note that we decided to define each of these individual roles tightly)</b>	Individuals who have or have had the condition under study; it may include patient surrogates or caregivers as well. It does not necessarily mean, but does not exclude, patient advocates or patient navigators.	<a href="https://pcornet.imeetcentral.com/p/aQAAAAACg4f3">https://pcornet.imeetcentral.com/p/aQAAAAACg4f3</a>	An individual affected by a condition, illness, or disease, and/or an individual who personally identifies as a patient and has sought or received care.
<b>Caregiver</b>			An individual who provides uncompensated care to a patient in a capacity outside of their professional responsibilities.
<b>Participant (replaces the word subject)</b>	An individual who is engaged in an activity related to their health. These individuals are affected by a condition or disease, or they are healthy; in either case they are engaged and empowered to participate in their own health and health decisions, including prevention, and clinical research.		A participant is an individual who is engaged in a research activity as a: <ul style="list-style-type: none"> <li>• <a href="#">Patient</a></li> <li>• <a href="#">Caregiver</a></li> <li>• Family member</li> <li>• Community member</li> </ul>

			<ul style="list-style-type: none"> <li>• Interest and/or affinity group member<sup>1, 2</sup></li> </ul>
<b>Health Systems Leader</b>	Hospitals and Health Systems: Organizations where care is delivered, including public and private hospitals and health systems, urgent care centers, retail health clinics, and community health centers, and organizations representing these facilities	<a href="http://www.pcori.org/funding-opportunities/what-we-mean-engagement/pcoris-stakeholders">http://www.pcori.org/funding-opportunities/what-we-mean-engagement/pcoris-stakeholders</a>	An executive or designated personnel from organizations where care is delivered, including public and private hospitals and health systems, urgent care centers, retail health clinics, and community health centers, and organizations representing these facilities.
<b>Stakeholders</b>	Includes clinicians (e.g., physicians, nurses, pharmacists, counselors, and other providers of care and support services); patient-advocacy groups; community groups; researchers; health-related associations; policy makers; and organizational providers, purchasers, payers, and industries for whom the results of the research will be relevant.	<a href="https://pcornet.imeetcentral.com/p/aQAAAAACg4f3">https://pcornet.imeetcentral.com/p/aQAAAAACg4f3</a>	<b>Participants</b> and groups (e.g., <b>patients</b> , physicians, nurses, pharmacists, counselors, and other providers of care and support services; patient-advocacy groups; community groups; researchers; health-related

<sup>1</sup> Couldn't any stakeholder be a participant depending on the study? Doctors? Hospital admins?

<sup>2</sup> Yes, if they are the subject of a research project focused on their stakeholder group. I know we struggled with this definition, but the goal of this definition is to shift the language we use (participant not subject) as opposed to really defining participant.

			associations; policy makers; health system leaders; and, organizational providers, purchasers, payers, and industries) for whom the processes and results of PCORnet research are relevant.
<b>Stakeholder Engagement</b>	The process by which patients and consumers become invested in their own health and take control of their care. Patients and consumers are to be treated as key stakeholders when making decisions about their health and health care.	<a href="https://pcornet.imeetcentral.com/p/aQAAAAACg4f3">https://pcornet.imeetcentral.com/p/aQAAAAACg4f3</a>	A bidirectional process by which <u>participants</u> , clinicians, and investigators collaborate on the development of meaningful patient-centered research. <sup>3 4</sup>
<b>Healthcare Professional<sup>5,6</sup></b>			An individual who is engaged in direct patient care.
<b>Participant reported data (PGD) (changed)</b>	Patient-generated data (PGD) is data that is created, gathered, or inferred by the patient or their proxy to help	<a href="https://pcornet.imeetcentral.com/p/aQAAAAAB_5gx">https://pcornet.imeetcentral.com/p/aQAAAAAB_5gx</a>	Data that are initiated, gathered, or inferred by the <u>participant</u> or their

<sup>3</sup> Co-develop is jargon (so recommended replacing this with collaborate)

<sup>4</sup> Co-develop implies a partnership and equitable contributions from all... collaborate is fine but does not necessarily communicate this expectation

<sup>5</sup> Should this be clinician, so we are consistent throughout?

<sup>6</sup> We should have a term that is inclusive of the entire care team, including all clinic staff.

<p><b>from Patient generated data)</b></p>	<p>address a health concern. PGD may include demographics, patient identifiers, health history, symptoms, biometrics, treatment history, lifestyle choices, vital signs, patient-reported outcomes (PROs) and other health-related data. Patients or their proxy are responsible for capturing or recording these data and directing the sharing or distribution of it to health care providers and other stakeholders. PGD may be recorded directly or derived from paper medical charts, electronic health records (EHRs), personal health records, personal health devices, or other sources.</p>		<p>proxy, excluding the clinician.<sup>7</sup></p>
<p><b>Participant Portal</b></p>	<p>A patient portal is a tool that providers can use to engage patients, enhance patient- provider communication, and improve patient outcomes. It is a secure online website that gives patients convenient 24-hour access to personal health information from anywhere within internet connection, and allows</p>	<p><a href="https://pcornet.imeetcentral.com/p/aQAAAAACg4f3">https://pcornet.imeetcentral.com/p/aQAAAAACg4f3</a></p>	<p>Secure, internet-based, application that <a href="#">participants</a> and other <a href="#">stakeholders</a> use to access or exchange health-related information relevant to patient-centered outcomes research.</p>

<sup>7</sup>Unclear what is meant by initiated.

Aren't all data for PCOR generated from participants?

Should this be "Participant Reported Data?" I think that biosensor data is different, and the intent with this concept is self-report.

	<p>patients to view health information such as recent doctor visits, discharge summaries, medications, immunizations, and lab tests. Many patient portals also allow patients to exchange secure email with their health care teams, request prescription refills, and perform other activities related to their health care.</p>		
<p><b>Patient-reported Outcomes (PROs)</b></p>	<p>Patient-reported outcomes (PROs) are a report of the status of a patient’s health condition by the patient or their proxy without interpretation by a clinician or anyone else. Proxy reports are only considered PROs if the proxy is the sole source of patient clinician communication (e.g. cognitive impairment, pediatrics, etc). PROs may address any aspect of a patient’s health and/or healthcare experiences, including mental health, physical health, social health, experiences of care,</p>	<p><a href="https://pcorner.imeetcentral.com/p/aQAAAAAB_5gx">https://pcorner.imeetcentral.com/p/aQAAAAAB_5gx</a></p>	<p>Patient-reported outcomes (PROs) refer to validated tools and approaches related to patient-centered outcomes research.<sup>8, 9,10, 11</sup></p>

<sup>8</sup> One recommendation for alternative definition: Participant generated data that provide assessments of health and well-being.

<sup>9</sup> Use the above definition. (To the person below) answers?

<sup>10</sup> While I certainly want the tools validated, is that really a requirement to use the term in PCORnet? That seems unnecessary as many will be exploratory and the definition of validated varies widely.

<sup>11</sup> My response to the above would be that what they described is PGD—PROs are a specific type of PGD

	<p>patient-reported behaviors, and treatment effects. They are often measured through standardized, validated instruments such as <a href="#">PROMIS</a> and <a href="#">SF Health Surveys</a>, and are sometimes called ePROs (Electronic Patient Reported Outcomes) or PROMs (Patient Reported Outcome Measures).</p>		
<p><b>View, Download and Transmit Requirements (VDT)</b></p>	<p>A part of Centers for Medicare and Medicaid Services' Meaningful Use core measures which calls for measures that provide patients the ability to view online, download, and transmit their health information within four business days of the information being available to the health provider.</p>		<p>Keep as defined</p>
<p><b>Community</b></p>			<p>A group of people who are linked by an affinity (e.g. social ties, common perspectives, joint action or concern, or geography).</p>
<p><b>Meaningful Engagement</b></p>	<p>Creating a mutually beneficial relationship in which all stakeholders (either a specific one or all) develop a shared vision for research based on a common understanding of what is being proposed. All stakeholders are viewed as equal participants, their expertise is</p>		<p>An active process characterized by shared vision, responsibility, and stewardship, where all <a href="#">stakeholders</a> are equally respected and their contributions to patient-centered outcomes</p>

	recognized, and their contributions are valued.		research are essential to its success.
<b>Principal Investigator or co-Principal Investigator</b>			Lead scientist(s) for a research project who has scientific, administrative, and leadership responsibilities for the entire project.
<b>Patient Principal Investigator or Patient co-Principal Investigator</b>	A Principal Investigator or co-Principal Investigator for research whose primary association with the condition is lived experience of the condition of interest.		A <a href="#">Principal Investigator or co-Principal Investigator</a> who brings a lived experience of the condition or community of interest as an equal investigator on the research leadership team.