ISMPP Patient Engagement Task Force

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Patient Engagement Lexicon

Engaging patients with the goal of improving health outcomes

Theme	Term (Abbreviation)	Alternative Terms	Description	Sources (With Links)
Patient Involvement and Engagement	Patient engagement	Patient/public involvement, Consumer involvement, Stakeholder engagement	Active involvement, collaboration and communication of patients, caregivers, patient organization representatives, and the public in healthcare research and delivery.	Healthcare Excellence Canada: https://www.healthcareexcellence.ca HRA NHS: https://www.hra.nhs.uk
	Meaningful engagement	Authentic engagement, Active participation, Effective collaboration	Ensuring patient contributions genuinely influence healthcare decisions and outcomes.	National Health Council: https://nationalhealthcouncil.org/additional-resources/glossary-of-patient-engagement-terms/
	Early-stage engagement	Early engagement	Involving patients at the initial stages of research planning and design to ensure that their perspectives shape project objectives, methodologies, and outcomes.	Patient Engagement Management Suite: https://pemsuite.org/
	Shared decision-making	Co-decision making	Collaborative process between healthcare providers and patients/caregivers to make informed healthcare choices.	National Health Council: https://nationalhealthcouncil.org/additional-resources/glossary-of-patient-engagement-terms/
	Patient empowerment	Patient autonomy, Self-advocacy	Enabling patients to have control over and manage their health actively and make informed choices.	National Health Council: https://nationalhealthcouncil.org/additional-resources/glossary-of-patient-engagement-terms/
Patient Roles and Advocacy	Patient advocate	Health advocate, Patient liaison, Patient champion	An individual who supports patients' rights, facilitates understanding of treatments and health systems, and advocates for the patient community.	ABPI Sourcebook: https://www.abpi.org.uk

	Expert patient	Informed patient, Peer support leader	Patient with extensive experience managing a health condition who educates and empowers others.	European Respiratory Journal: https://publications.ersnet.org/content/erj/44/4/853
	Patient thought leader (PTL)	Patient opinion leader (POL)	People with proven experience and expertise of a health-related topic as patients themselves or as caregivers, who are trusted and well-respected influencers.	N/A
	Patient organization representative	Patient advocacy group (PAG) representative, Non-governmental organization (NGO) representative, Patient and public involvement (PPI) representative	Represents organizations supporting patient interests and advocating patient rights. They may or may not have lived experience of a condition.	ABPI Sourcebook: https://www.abpi.org.uk National Health Council: https://nationalhealthcouncil.org
	Caregiver/carer	Family/friend caregiver, Care partner, Care provider, Support Partner	Provides support or care to patients, typically in a non-professional role.	ABPI Sourcebook: https://www.abpi.org.uk
Reporting and Communication	Plain language summary (PLS)	Lay abstract, Lay summary	Non-technical summary of a scientific article summarizing key findings for non-specialist audiences. They can summarize congress abstracts or journal articles.	Plain Language Summaries: https://www.plainlanguagesummaries.com/

	Plain language summary of publication (PLSP)	Summary of research article (SRA)	Non-technical, peer-reviewed, citable summary of a previously published article.	Adis/Springer via Plain Language Summaries: https://www.plainlanguagesummaries.com/
	Patient perspective article	Patient viewpoint piece, Patient commentary	Articles reflecting patients' insights on healthcare experiences or issues.	N/A
	GRIPP2	GRIPP	Checklist for reporting patient/public involvement in research, promoting best practice.	BMJ Article on GRIPP2: https://www.bmj.com/content/358/bmj.j3453
Patient-Centred Approaches	Patient-centred	Person-centred, Patient-focused, Patient-oriented, Patient-led	Care approach prioritizing patients' needs, preferences, and values.	National Health Council: https://nationalhealthcouncil.org
	Patient experience	Healthcare experience, Patient satisfaction, Patient journey	Patients' overall interactions and perceptions of healthcare delivery.	National Health Council: https://nationalhealthcouncil.org
	Patient-focused medical product development	Patient-focused medicine development (PFMD), Patient-focused drug development (PFDD)	A systematic approach to help ensure that patients' experiences, perspectives, needs, and priorities are captured and meaningfully incorporated into the development and evaluation of medical products throughout the medical product life cycle.	US Food and Drug Administration: https://www.fda.gov/drugs/development-approval-process-drugs/patient-focused-drug-development-glossary
Patient Data and Outcomes	Patient experience data (PED)	Patient-reported experience measure	Data that captures patients' experiences, perspectives, needs, and priorities related to the symptoms of their condition and its	US Food and Drug Administration: https://www.fda.gov/drugs/development-approval-process-drugs/patient-focused-drug-development-glossary

		(PREM), Patient insights data, Patient satisfaction data	natural history, the impact of the conditions on their functioning and quality of life, their experience with treatments, input on which outcomes are important to them, patient preferences for outcomes and treatments, and the relative importance of any issue as defined by patients.	
	Patient-generated health data (PGHD)	Patient-reported data, Self-reported health data	Health data collected directly from patients outside clinical settings.	National Health Council: https://nationalhealthcouncil.org
	Patient-reported outcome (PRO)	Patient-reported outcome measure (PROM), Patient outcome measure, Patient self-report	Health outcomes directly reported by patients, assessing treatment/intervention effectiveness. A PRO is a type of clinical outcome assessment (COA), which describe or reflect how a person feels, functions, or survives and are used in research studies.	National Health Council: https://nationalhealthcouncil.org US Food and Drug Administration: https://www.fda.gov/about-fda/division-patient-centered-development/clinical-outcome-assessments-coas-medical-device-decision-making
Inclusivity and Fairness	Representativeness	Inclusiveness, Demographic representation, Diversity	Ensuring samples/groups reflect diverse global populations accurately.	National Health Council: https://nationalhealthcouncil.org
	Fair market value (FMV)	Market price, Patient compensation, Equitable value	Standard compensation reflecting the true market value of patient contributions.	Patient-Focused Medicine: https://patientfocusedmedicine.org National Health Council: https://nationalhealthcouncil.org
	Health literacy	N/A	The degree to which individuals have the capacity to obtain, process, and understand basic health information and services	US Food and Drug Administration: https://www.fda.gov/drugs/development-approval-process-drugs/patient-focused-drug-development-glossary

			needed to make appropriate health decisions.	
	Health numeracy	N/A	The ability to understand and use numerical information in the context of healthcare, as a key component of health literacy.	National Numeracy: https://www.nationalnumeracy.org.uk/

Research Collaboration	Collaborative research	Co-production of research, Participatory research	Research partnering patients and researchers through all research stages.	National Health Council: https://nationalhealthcouncil.org
	Community-based participatory research (CBPR)	N/A	Collaborative research actively involving community members as partners.	National Health Council: https://nationalhealthcouncil.org