EXPANDING THE SCIENCE OF PATIENT INPUT:
The Power of Language

"The term
'**patient engagement**'
is unevenly used and
poorly defined."

-*FASTERCURES* WORKSHOP PARTICIPANT

200
TERMS AND
DEFINITIONS

24 TERMS WITH
MULTIPLE
DEFINITIONS

UP TO
7
DEFINITIONS FOR A
SINGLE
TERM

LANGUAGE MATTERS. At a February 2016 workshop of leaders committed to expanding patient engagement hosted by *FasterCures*, **JUST 22 PERCENT FELT THERE WAS BROAD AGREEMENT ON WHAT THE TERM "PATIENT-CENTERED" MEANS OR REPRESENTS.** The need to craft a common language emerged as one of the key takeaways from that meeting. The diversity of terms and definitions reflect a nascent field still coming together, but can be confusing when trying to move forward and identify the essential elements of what makes an activity patient-centered. Add to the mix different definitions for the same terms used by regulators, health-care providers and patients themselves **AND IT'S EASY TO SEE WHY A SHARED TAXONOMY OF TERMS IS A VITAL STEP IN ADVANCING THE SCIENCE OF PATIENT INPUT.**

Yet, reaching consensus about the language we use is easier said than done. We all want to be able to use terms and definitions that fit our particular needs and the context in which we operate. To help us move collectively toward a common language that supports the science of patient input, *FasterCures* reviewed more than 100 public documents and websites and found nearly 200 terms related to patient engagement. In this report we share key findings and recommendations.

IN OUR SCAN, THESE FOUR TERMS TURNED UP MOST FREQUENTLY AND HAD THE GREATEST NUMBER OF UNIQUE DEFINITIONS:

1. **PATIENT CENTRICITY**
2. **PATIENT ENGAGEMENT**
3. **PATIENT PREFERENCES**
4. **PATIENT PERSPECTIVE DATA**

We dive deep into the various uses of these four terms to illustrate how different sectors and contexts are shaping meaning as a step toward greater shared understanding.
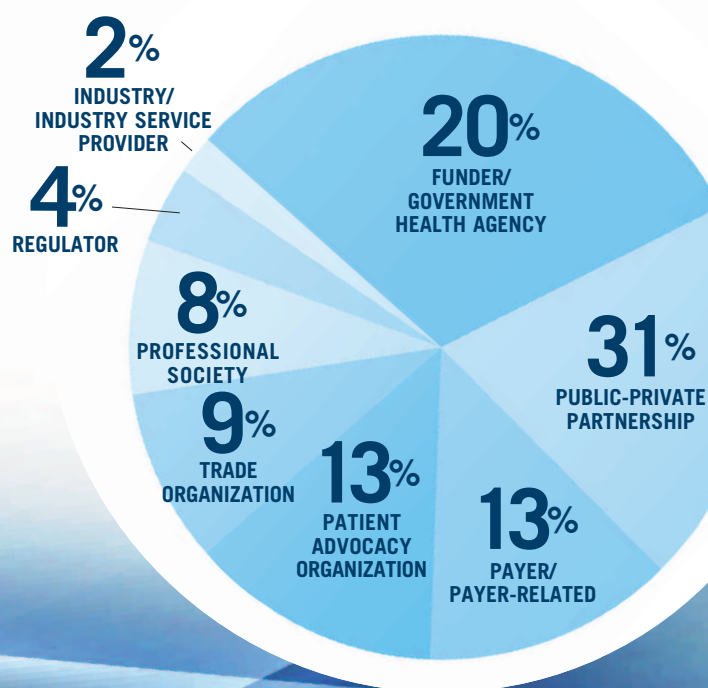
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Toward a Common Language

THREE OBSERVATIONS

1 Two sectors combined contribute more than half of the terms and definitions related to patient engagement.

2 Regulators independently contribute relatively few terms, but play an active role in public-private partnerships that produce nearly one-third of the terms in use.

3 Independent contributions from patient organizations represent just 13 percent of terms identified, but they contribute through other sectors.

OUR STARTING POINT: From our search, *FasterCures* identified nearly 50 organizations contributing terms and definitions through their public websites and materials. We categorized the organizations according to sector or their primary role in the ecosystem and then classified each term by sector and its context of use.

CONTRIBUTION BY SECTOR

2% INDUSTRY/ INDUSTRY SERVICE PROVIDER

4% REGULATOR

20% FUNDER/ GOVERNMENT HEALTH AGENCY

8% PROFESSIONAL SOCIETY

9% TRADE ORGANIZATION

13% PATIENT ADVOCACY ORGANIZATION

31% PUBLIC-PRIVATE PARTNERSHIP

13% PAYER/ PAYER-RELATED

TERMS **134** **191** UNIQUE DEFINITIONS

BOTTOM LINE

With so many sectors involved in creating terms and definitions, the language of patient engagement risks being a servant to many masters and useful to none.

Understanding Context

LANGUAGE IS CONTEXTUAL. In the tables that follow, *FasterCures* examines four terms and their definitions by sector and context of use. We offer observations about "who" is using the terms "when" as a means to advance the conversation.

TERM: PATIENT CENTRICITY

SECTOR	CONTEXT	DEFINITION HIGHLIGHTS
INDUSTRY/ INDUSTRY SERVICE PROVIDER	R&D	Shifting from medicine or physician-focused approach to a patient-centered approach by understanding the patient experience, understanding the condition across patient types, and using this information to shift culture toward what works for patients and addressing their needs.
INDUSTRY/ INDUSTRY SERVICE PROVIDER	R&D	Process of designing a service or solution around the patient such that you can't do anything (e.g., write a protocol) without a discussion with patients and getting their input.
FUNDER/ GOVERNMENT HEALTH AGENCY	HEALTH CARE	Aims to improve health-care quality by providing patients and physicians with state-of-the-science information about which treatments work best for a given condition.
TRADE ORGANIZATION	HEALTH CARE	Necessary to improve quality and value of care and involves giving patients access, support and information to take charge of their health.

BOTTOM LINE

A lack of specificity at this early stage is not necessarily surprising or negative, but moving toward consistency within sectors and contexts is a critical next step.

Within the same sector, a different context of use may lead to unique definitions for the same term.

TERM: PATIENT ENGAGEMENT

SECTOR	CONTEXT	DEFINITION HIGHLIGHTS
FUNDER/ GOVERNMENT HEALTH AGENCY	R&D	Meaningful involvement of patients across entire process (focus, design, conduct and dissemination).
FUNDER/ GOVERNMENT HEALTH AGENCY	HEALTH CARE	Involvement of patients and family members to improve quality and safety and facilitate the creation of partnerships between health professionals and patients/family members.
TRADE ORGANIZATION	R&D	Add patient-driven data that reflect a range of patient perspectives on condition severity and unmet medical needs over time.
TRADE ORGANIZATION	HEALTH CARE	Patients, families, representatives and health professionals working in partnership across health system to improve health and health care.
PAYER/ PAYER-RELATED	HEALTH CARE	Encouraging and supporting patients and families to be active participants in decision-making, including sharing their stories and participating on boards, workgroups and advisory councils.
PUBLIC-PRIVATE PARTNERSHIP	R&D	Meaningful and active collaboration in governance, priority setting, research conduct and knowledge translation.
PUBLIC-PRIVATE PARTNERSHIP	R&D AND HEALTH CARE	An effort to extend the benefits of incorporating patient insights, experiences, desires and preferences from bench to bedside.

BOTTOM LINE

Advancing the science of patient input requires a taxonomy of commonly agreed upon terms and definitions, with well-defined relationships to one another, which vary as needed by context.

TERM: PATIENT PERSPECTIVE DATA

SECTOR	CONTEXT	DEFINITION HIGHLIGHTS
TRADE ORGANIZATION	R&D	Using a scientific approach to focus on patients' needs and identifying ways to provide meaningful treatments and information for patients and medical professionals.
PATIENT ADVOCACY ORGANIZATION	R&D AND HEALTH CARE	Includes data related to burden of disease gathered using structured approaches on patient preferences and patients' minimum expectation of benefits and maximum tolerable harms or risks that patients are willing to accept.
FUNDER/ GOVERNMENT HEALTH AGENCY	HEALTH CARE	Gathered using survey methods to allow for objective and meaningful comparisons of hospitals on topics that are important to consumers.
REGULATOR	R&D	A type of patient input about patients' experiences with a disease or condition and its management that may be used to understand the disease or condition, understand its impact on patients, identify outcomes most important to patients and understand benefit-risk tradeoffs for treatment.

OBSERVATION

These definitions focus on methods used to gather patient preferences or perspective data, rather than specifying what the data should be.

BOTTOM LINE

A taxonomy of terms will provide the foundation from which methods, measures and outcomes of patient input can be built.

Some concepts cut across contexts.

TERM: PATIENT PREFERENCES

SECTOR	CONTEXT	DEFINITION HIGHLIGHTS
PATIENT ADVOCACY	R&D AND HEALTH CARE	Trade-offs, decisions and choices made by individuals to determine absolute or relevant importance of product attributes, features and outcomes.
PROFESSIONAL SOCIETY	R&D AND HEALTH CARE	Measuring patient's value for component/attribute, can be absolute or relative, if relative then requires trade-offs, with the goal of a more desirable composite outcome.
PUBLIC-PRIVATE PARTNERSHIP	HEALTH CARE	Expressed by patients regarding decisions about health care.
REGULATOR	R&D	Measuring, using qualitative or quantitative assessments, relative desirability or acceptability of attributes that may affect benefit-risk considerations, includes studies designed to measure the attributes patients prefer.

BOTTOM LINE

For terms such as "patient preferences" that are supported by an established body of knowledge, there was more overall agreement in definitions being used – a positive direction to guide our work.

Talking the Talk

A focus on patient needs and expectations is reshaping the biomedical enterprise. Patient perspectives are informing priorities for early-stage research, shaping attributes of new medical products and guiding how health-care services are delivered. This expansion of patient-centered activities has given rise to a whole new language, with a proliferation of terms to describe both intent and action.

BE CLEAR AND TRANSPARENT about the context and goal of your communication – who is it intended to reach?

STEER CLEAR of using the term as part of the definition (e.g., "Patient engagement is engaging patients")

RESIST CREATING NEW TERMS before considering how existing ones might be adapted to your context of use

ADOPT TERMS AND DEFINITIONS to use consistently within and outside your organization

EMPLOY PROPER GRAMMAR: Does your term define a noun, a verb or an adjective?

CONSIDER THE PERSPECTIVES of other sectors to help language be a bridge from one setting to another (e.g., from a research study to the doctor's office)

BOTTOM LINE

Now is the time to come together across the ecosystem to build a shared taxonomy.

PatientsCount
THE SCIENCE OF PATIENT INPUT

ABOUT PATIENTS COUNT

Through its Patients Count program, *FasterCures* aims to improve health by expanding opportunities for patients' perspectives to shape the processes by which new therapies are discovered, developed and delivered. We do this by expanding the capacity of academics, industry and patient organizations to build upon the science of patient input; fostering patient-centric policies and practices that enable greater patient participation in decision-making; and advancing the dialogue on the benefits of patient-centricity across the medical product lifecycle.

ABOUT *FASTERCURES*

FasterCures, a DC-based center of the Milken Institute, is driven by a singular goal – to save lives by speeding up and improving the medical research system. We work across sectors and diseases to accelerate the process by which great advances in science and technology are turned into meaningful medical solutions for patients.

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