

Table 1. Extensions to the ONC Roadmap Stakeholder Perspectives

Note: Role definitions are provided following the stakeholder table

Roadmap Label	Roadmap Definition	Role	Value Proposition*	Barrier
<p>Persons who receive care or support the care of others</p>	<p>Individuals, consumers, patients, caregivers, family members serving in a non-professional role and professional organizations that represent these stakeholders' best interests</p>	<p>Data generator Data provider Data mediator End User Decision Maker Influencer Recommender Provocateur Patient advocate</p>	<ul style="list-style-type: none"> • More access to correct information • Up to date information of care of individuals • Ability to provide input from the perspective of both patient and caregiver with treatment plan • Ability to coordinate in around and about care by caregiver in one setting or point of care. • Care coordination in around and about the whole patient story (physical, cultural, behavioral, etc.) • Ability to access and see record in real time. • Ability to make correction of information entered incorrectly • Input from patient or caregiver perspective 	<ul style="list-style-type: none"> • Lack of access of available information • Lack of education in how to use the data and what to do about it. • Health literacy and information literacy • Lack of patient ability to correct errors in their records • Lack of consistent ability to input personally generated information, e.g. fit bit, glucometer, pacemaker , etc.

<p>Persons and organizations that deliver care and services</p>	<p>Professional care providers who deliver care across the continuum, not limited to but including hospitals, ambulatory providers, public health providers, retail and other pharmacies, laboratories, behavioral health including mental, retail health innovations such as house calls, home visits, virtual visits and telehealth</p> <p>health and substance abuse services, home and community based services, long term care providers, respite providers, nursing homes</p> <p>and professional organizations that represent these stakeholders' best interests</p>	<p>End User</p> <p>Decision Maker</p> <p>Influencer</p> <p>Recommender</p> <p>Financer</p> <p>Provocateur</p> <p>Saboteur</p>	<ul style="list-style-type: none"> • Enable patient centeredness, patient participatory and patient engagement in the optimum level of wellness • Ability to provide effective management of health • Ability to provide better care for patient at the point of care • Ability to monitor patient during their length of stay and adjust their care accordingly • Better care of specific patient population • Benefit from research that comes from data • Better care focusing on individual and population level • Potential for minimizing risk in the delivery of healthcare services • More information can lead to better decisions • Minimize risks 	<ul style="list-style-type: none"> • Lack of standard of practice for sharing and transfer of data • Lack of the ability to share data in a clear, trusted, accurate, complete and easily understood way • Lack of data integration ability • Lack of technical standards
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<p>Organizations that pay for care</p>	<p>Private payers, employers and public payers that pay for programs like Medicare, Medicaid and Tricare, American Red Cross, faith-based, VA, DoD, and many other non-governmental groups</p>	<p>End User Decision Maker Influencer Recommender Financer Provocateur Saboteur</p>	<ul style="list-style-type: none"> • Profitable use of large datasets • Cost reduction through better access and use of information • Better outcomes through actionable information 	<ul style="list-style-type: none"> • Different business practices • Incompatible technical systems • Lack of trust in payers • Lack of skills in analytics
<p>Persons and organizations that support the public good</p>	<p>Federal, state, tribal and local governments, public health agencies; philanthropies, NGOs</p>	<p>End User Decision Maker Influencer Recommender Provocateur Saboteur</p>	<ul style="list-style-type: none"> • Expansion of the definition of who are the people and organizations that support public good (including and not limited to public health agencies, NGOs, charitable org., professional org, advocacy groups, support groups, etc.) 	<ul style="list-style-type: none"> • Very linear and one dimensional definition • Lack of access to information • Lack of technical compatibility between systems • Lack of knowledge of how to access • Lack of processes to support coordinated care
<p>Persons and organizations that generate new knowledge, whether research or quality improvement</p>	<p>Researchers, population health analytics, quality improvement knowledge curators, quality measure stewards, clinical trial and research organizations, philanthropies, NGOs</p>	<p>End User Decision Maker Influencer Recommender Financer Provocateur Saboteur</p>	<ul style="list-style-type: none"> • Decreased time to implementation of new methods • Improved effectiveness in data dissemination 	<ul style="list-style-type: none"> • Lack of data interoperability • Lack of adequate resources

<p>Persons and organizations that provide health IT capabilities</p>	<p>Technology developers for EHR and other health IT, including but not limited to health information exchange (HIE) technology, laboratory information systems, personal health information technologies, pharmacy systems, mobile technology, medical device manufacturers, laboratory/genomic organizations, and other technology that provides health IT capabilities and services</p>	<p>Influencer Financer Provocateur Saboteur</p>		
<p>Persons and organizations that govern, certify and/or have oversight</p>	<p>Governing bodies and accreditation/certification bodies operating at local, regional, or national levels that provide a governance structure, contractual arrangements, rules of engagement, best practices, processes and/or assess compliance</p>	<p>End User Decision Maker Influencer Recommender Financer Provocateur Saboteur</p>		
<p>Persons and organizations that develop and maintain standards</p>	<p>Standards development organizations (SDOs) and their communities of participants, such as technology developers, health systems, providers, government, associations, etc.</p>	<p>Decision Maker Influencer Recommender Provocateur Saboteur</p>		



Stakeholder Role Definitions

Data generator: Patient's / Individuals / Family and Caregivers.

Data: Smallest units – numbers, words, sentences or pictures derived from patients or individuals. A single piece of data has no meaning.

Information: Data with Meaning. Information is the facts and ideas that come from data with context. So 110 may have no meaning but 110 in a screen labeled “Systolic Blood Pressure” represent a physical observation.

Knowledge: Information that has been brought together and relationships become realized. Knowledge answers questions like “how” or “why”. The transformation of information to knowledge is a continuum of increasing understanding through pattern discovery, and relationship realization. So now a 110 systolic blood pressure (as above) can be added to the rest of the story, age of patient, height, weight, medications, urine output, etc. to form knowledge.

Wisdom: Applicable use of knowledge to solve human problems. The difference between knowledge and wisdom is like the difference between memorizing and understanding. It requires the highest level of critical thinking

Decision Maker: Data- Individual, organization, researcher.

Data mediator: Individual or organization that help resolve conflicts regarding the meaning of data by facilitating negotiation and dialogue between or among parties with different views of the subject.

Data provider: Individual or business entity who provides their own data or data from one or a population of many.

End-user:

Related to use of data within a LHS:

LHS: Individual or ultimate user of health and healthcare data for primary usage or various secondary usage. Patient/Family/Caregiver, healthcare facility, health or healthcare researcher

When identifying End-users ask- is this Individual, facility, system or organization going to benefit from the data or data use for primary or secondary usage.

Related to use of LHS: The definition becomes much broader

Provocateur/Influencer: Individual, group, or organization with motivation to test perspectives both pro and con through means of disruption

Saboteur: Related to LHS- Individual, group, or organization with motivation to weaken or destroy the goal or policy through various means; subversion, obstruction, disruption or destruction.

Intentional: Developers not wanting to share coding, or providers not motivated to share data.

Unintentional: Patient or provider not using the system in the way it was intended- so benefits are negated.

Example: application of security to a product that is so tight it precludes use.

Rationale for defining this role: Attention and inclusion of individuals, groups or organizations in this role is of utmost importance to mitigate and educate on benefits and avoid unintended consequences.