

Health Data is			
Wellness	9	wellness, health	● ● ● ● ● ● ● ● ● ●
	7	medical, provider records, lab results	● ● ● ● ● ● ●
Quality of life	6	live the best life possible, wellbeing, quality of life	● ● ● ● ● ●
Disease prevention / treatment	6	pertinent to prevention and management of illness, disease, future cures, biology of a disease and a person's outcomes, personalized medicine solutions,	● ● ● ● ● ●
	4	physical activity	● ● ● ●
Patient reported	3	change in health status deemed relevant by patient, patient reported, observations	● ● ●
Varying sources	3	information from a variety of sources, all data from any source, lifetime data	● ● ●
	2	Mine, my personal health info	● ●
	2	health of a population	● ●
	1	psychological	●
Decisions about patient health	1	sociodemographic	●
	1	information that ...[impacts] regulatory, physician, patient decision making	●

Who can access it			
Patient	11	patients, me, we all, individuals	● ● ● ● ● ● ● ● ● ● ● ●
Provider	10	providers, doctors	● ● ● ● ● ● ● ● ● ●
Payer	6	payers, my insurer	● ● ● ● ● ●
Family	5	family members, caregivers, family	● ● ● ● ●
Companies, health systems	5	systems, industry, companies, technology	● ● ● ● ●
Consent	5	those that patients give permission/consent to	● ● ● ● ●
Research	4	schools, researchers, pharma companies, therapy developers	● ● ● ●
	4	everyone, anyone	● ● ● ●
	3	regulators	● ● ●
	2	patient organizations, advocate organizations	● ●
	1	the right people	●
	1	no one	●

Challenges

Gaps in patient knowledge	8	patients don't understand how to consume healthcare, how to navigate process, where data is, being an informed patient, patients aren't aware how much is collected about/from them	● ● ● ● ● ● ● ●
Data integrity	6	Validity, reliability, completeness, equal representation from all patients, quality/consistency of data, patient reported outcomes in the loosest sense take too long to validate	● ● ● ● ● ●
Lack of access	5	Access, not sure who or how to ask to get what they need, understanding how to get data, not all systems make data easily available and accessible to patients	● ● ● ● ●
Privacy	5	abuse of privacy, not consented, integrity of data collectors, patients being identified	● ● ● ● ●
Interpretation of data	5	appropriate analysis for various contexts to be meaningful for all stakeholders, understanding what data means, not all data is easily understandable, integrity of analysts, tools, platforms, people are needed to help interpret the data, indecipherable to most lay people, patients don't understand how to use data	● ● ● ● ●
Incentives	4	financial incentives work against patients, incentives not aligned from sharing (even when people say they want to), no incentives to providers to share	● ● ● ●
Interoperability	3	interoperability of medical records, incompatible IT systems (business/tech reasons), incompatible data	● ● ●
Lack of standardization	3	inconsistency of collection, standardization of data collection, methodologies for collection accepted by decisions makers	● ● ●
Sharing	3	sharing is difficult, digital solutions to sharing, understanding where data goes	● ● ●
Ownership	3	identifying/clarifying ownership, individuals aren't at the center, possessing and controlling their own data, what's mine is mine	● ● ●
Resources	2	requires infrastructure, costs and support, funding (pay HR for entering, cleaning data)	● ●
Medical community	2	medical community must get on-board. It cannot have a lock on medicine, health system alignment to collect and share data	● ●
Regulation	2	legal/regulatory provisions, HIPAA and other regulations	● ●
	2	finding the best care, understanding options	● ●
	1	EMRs definition of real world evidence	●
	1	technology is partly there but needs to get better	●
	1	clinicians getting scooped	●

Data includes			
Medical interpretations	15	patient records, EMRs, symptoms, clinical outcome assessment, clinical results, reports, EHR progress notes	● ● ● ● ● ● ● ● ● ● ● ● ● ● ● ●
Objective measures of health	12	lab data, numerical data, objective measures of health, vital signs, blood work, test results, quantitative, physiological, imaging	● ● ● ● ● ● ● ● ● ● ● ●
Trackerd data	8	movement, trackers, activity logs, high freq longitudinal data from non-invasive sensors, devices	● ● ● ● ● ● ● ●
Patient reported	7	patient goals, patient reported outcomes, end pt, qualitative	● ● ● ● ● ● ●
	4	the right information, everything about your health or lack of, everything about me	● ● ● ●
	3	emotions, mental	● ● ●
	3	genetic information, omics	● ● ●
	2	observations from family/social circle	● ●
	2	diet	● ●
	2	medicines, neutraceuticals	● ●
	2	world data, surveys	● ●
	1	real world evidence	●
	1	payer information	●
	1	demographics	●
	1	appointment info	●

When can they access it

Patient care	7	they need to do the right thing, need to take care of me	● ● ● ● ● ● ●
Developing treatments	5	in aggregate to make other's health better, approved for research to improve treatments & care, help others like me, developing a drug, reviewing drug for approval	● ● ● ● ●
Anytime	4	anytime, when they want to (it's theirs)	● ● ● ●
Anonymous	3	de-identified, anonymity, (un)traceability, information hub	● ● ●
Consent	3	patient gives consent, owner permits access, patient provides it	● ● ●
	1	similar to financial records	●
	1	trial completion	●
	1	ask for it	●
	1	decisions between physician and payer	●
	1	they try really hard to access it	●
	1	when we get our act together	●
	1	never	●

To get citizens involved

Educate about Data	11	educate, teach people how to access their data, explain what health data is and why they want to understand it, where data is, why it's important & what can be done with it, explain purpose, bg, need and value, have citizens know data not already shared	● ● ● ● ● ● ● ● ● ● ● ●
Empower	5	provide opportunities for them to become citizen scientists, empower patients, empower with technology and platforms to leverage the technology and connect with each other, use different modalities, opportunities, culturally + linguistically appropriate methods	● ● ● ● ●
Give them data	5	provide data back to citizens, make it easy for people to access their data, make info available via an easy-to-understand app, provide a place for their data to go and control of it, return meaningful data to patients	● ● ● ● ●
Standards, integrations	3	systems need to be integrated, standards for health system data accessibility	● ● ●
Public campaign	2	raise awareness of what we all mean, public campaign	● ●
Incentives	2	reward system must be retooled to incentivize participation	● ●
Educate about healthcare	1	patients need to understand the healthcare system	●
World data	1	real-world evidence and big data should be included to increase the quality of healthcare	●
	1	need to reach the underserved	●
	1	tell stories that are compelling	●