HARVARD Kennedy School
ASH CENTER
for Democratic Governance
and Innovation

TABLE I: TYPOLOGY OF EIGHT HEALTH INFORMATION INITIATIVES

Name	Number of patients	Frequency of engagement	Access to information and data	Actionability	Personalization	Data sharing	Connecting	Technology
1. ImproveCareNow	28,000 pediatric patients.	Twice a year at community conferences; periodic webinars.	In person meetings and webinars, portal, ICN Exchange and blog posts provide access to information on research. Blog posts give voice to patient stories. Patients cannot access ICN2Registry data.	The website contains actionable patient resources, such as patient-developed toolkit on ostomy.	The information is not returned in formats that take into account patients' health literacy, culture and cognitive abilities.	Active data are collected during clinical encounters and inserted into ICN2Registry. Active and passive data collected by pilot apps to conduct N of 1 studies.	Patients and caregivers connect with peers and clinicians at bi-annual conferences and webinars.	ImproveCareNow.org portal. Connected wearable devices. Pilot apps.
2. Swedish Rheumatology Quality Register	60,000 patients, about half self-report patient outcomes.	Prior to clinical encounters.	Through a patient portal, patients can access their health data and visualize their disease activity over time.	Data can be used jointly with clinicians for care decisions.	Data is not returned in formats that take into account patients' health literacy, culture and cognitive abilities.	Patients use patient portal to input data on pain, fatigue, tender and swollen joints. Patient reported outcomes feed into registry.	Patients and clinicians connect during visits and discuss patient data to understand response to different medications and co-decide on treatment plan.	Patient portal, shared dashboard.

3. MyHealthTeams	Over 1.75 million members, across 29 disease communities.	30-60% of members log in once a month. Engagement varies by community: 30% of breast cancer community members engage monthly, 60% of Parkinson's community members engage monthly.	Patients can access forum, resources, Q&A section, infographics, information on side effects, life hacks and emotional support.	Infographics and answers to patients' questions are actionable.	Some of the answers to patients' questions are personalized because they take into account circumstances described by the patient in original question.	Patients share active data on their demographics, diagnosis, symptoms, treatment and medications when filling out their profile and when they communicate with members.	Patients connect with peers with the same chronic condition to share information and support.	Web app, mobile apps.
4. Breast Cancer Straight Talk Support Facebook Community	14,000 breast cancer patients and survivors.	850 posts daily.	Side effects, symptoms, treatments, life hacks.	Some of the information is actionable because it is based on patient experience and provided in simple terms.	Some of the answers to patients' questions are personalized because they take into account circumstances described by the patient in original question.	Patients share data on their type of cancer, treatment, medications and share pictures of scars, radiation burns and rashes to get feedback from members.	Patients connect to get information but also to vent, put their story into perspective, reduce social isolation and get emotional support to face cancer.	Web app, mobile app.

5. Tidepool	n/a	Before clinical encounters, more often for patients who are able to use diabetes data autonomously.	Patients can visualize diabetes data from different devices on a single platform. They can store historic data on Tidepool to understand trends.	The information is actionable for more sophisticated patients, who can use it to make insulin adjustments.	Data is not returned in formats that take into account patients' health literacy, culture and cognitive abilities.	Patients upload data from their insulin pump, continuous glucose monitor, and glucose meter. Patients and providers can add notes. Patients can share their data with providers, family members.	Patients share data with their providers to get help interpreting blood glucose fluctuations. Data drives more informed clinical encounters and helps identify teachable moments to improve diabetes self-management.	Patient portal, mobile app.
6.OpenNotes	20 million patients can access notes using patient portals.	n/a Frequency of access may be higher for patients with chronic condition. Reminders that notes are available drive access.	Clinical notes typed into patient's health record by physicians, nurses, therapists.	Information on care plan, follow up tests and future appointments may be actionable.	The information is not returned in formats that take into account patients' health literacy, language, culture and cognitive abilities.	Patients at some hospitals provide feedback on their notes and identify errors or omissions. OurNotes pilot will ask patients at four hospitals to contribute health history and goals for visit prior to seeing physician. Their input will become part of their notes and be incorporated into electronic health record.	Patients develop trust in their physicians and may be able to have more productive clinical encounters. Patients who can contribute feedback or content for their notes establish closer relationship with physician.	Patient portals. Notes may also be provided in hard copy.

7. IBD Partners	15,500[1]	3,000 members logged in once; 100 members logged in 5 times..	Information on IBD research. Patient profile and dashboard containing personal data on disease activity, pain, fatigue, anxiety, mood and sleep and exercise data from connected wearable devices.	The data is not actionable. More sophisticated patients may interpret the data to identify correlations and derive guidance.	Data is not returned in formats that take into account patients' health literacy, culture and cognitive abilities.	Patients are asked to fill out a baseline survey and update surveys every six months. They can connect wearable devices tracking exercise and sleep. They can fill out quick health check in questions when they log in.	Patients connect with other patients and with researchers in online forum to propose research questions, discuss and vote on research questions and define a patient-driven research agenda.	Online portal. Connected wearable devices.
8. Health eHeart Study	160,000 people consented, 141,000 provided basic information.	n/a	Information on research through the newsletter and online forum. Patients can access some of the data they contributed.	The data is not actionable.	Data is not returned in formats that take into account patients' health literacy, culture and cognitive abilities.	Patients fill out detailed surveys on demographics, health habits, family history. They can add lab results, connect wearable devices, their Facebook account and electronic health record.	Patients connected with researchers at research summit for prioritization. More active patients participate through Health eHeart Alliance and cause groups. Online forum is not very active.	Online portal, Eureka app to conduct research and N of 1 trials, wearable devices to measure activity, blood pressure, hearth rhythm and wireless scales.

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[1] This number includes members who signed up with the portal and members who joined the initiative before the portal was created.