| **#** | **Data involved** | **Stakeholders involved** | **Data flows** | **Data flow problems** | **Cause** | **Effect** | **Source** |
| --- | --- | --- | --- | --- | --- | --- | --- |
| 1 | Data providers: CPT (treatment), ICD-9 (outcomes of treatment), DRGs (diagnosis) | The stakeholder groups involved can be represented in a triangle: (1) Providers, employer groups (= the sponsors of the insurance model) and (2) government groups and (3) employees and members (Medicare/Medicaid), (4) payers (i.e., his stakeholder group) |  |  |  |  | PY1\_DI, Pos. 12 |
| 2 | Provider data link is most important |  |  |  | Provider data (= medical treatment data) is rich, complex, and required timeliness |  | PY1\_DI, Pos. 14 |
| 3 |  | Payers, providers, employers & government groups, and employees and members | Employers send eligibility information to payers. Payers send financial and outcome information back. Employees and members can check on eligibility and claims status, track activities of their wellness programs and payers pay out bonuses for that. |  |  |  | PY1\_DI, Pos. 18 |
| 4 |  |  |  | There is a lot of variation/lack of standardization in communication/data flow channels | Some people call, some people fax, some people use the digital system they provide |  | PY1\_DI, Pos. 20 |
| 5 |  |  |  | Have to manage these different groups in all these different ways: those that use electronic methods, those that don't use electronic methods at all and those who use some of them. |  | Train customer service in different ways | PY1\_DI, Pos. 22 |
| 6 | Healthcare data | Provider, payer |  | Healthcare data is siloed i.e., fragmented and spread across the HC system |  | Anyone looking at healthcare data is trained/assumes that they only see a fraction of that data | CS1\_DI, Pos. 4/60-64 |
| 7 | Claims | Provider-to-payer, payer-to-provider | Primary data flow: Claim flow/RCM/the flow of getting paid (via X12 and its family of standards, e.g., 4010, 5010): 837, 835, 277, 834, etc. |  | It is somewhat standardized, it is ubiquitous | Claim flow/RCM/the flow of getting paid gets used both within and between organizations as the primary articulation of delivery of care, i.e., it is used for purpose flows other than getting paid | CS1\_DI, Pos. 8/160-204 |
| 8 | Eligibility data | Provider-to-payer, payer-to-provider | Eligibility flow, using another set of those X12 transactions |  |  | It is somewhat standardized, it is ubiquitous | CS1\_DI, Pos. 8/205-208 |
| 9 | Approval data | Provider-to-payer, payer-to-provider | Utilization management to manage risk, i.e., treatment approval, using another set of those X12 transactions |  |  | It is somewhat standardized, it is ubiquitous | CS1\_DI, Pos. 8/208-221 |
| 10 | Clinical data | Providers, health information exchanges & networks | Provider to points of aggregation flows | Providers to points of aggregation flows are not scalable | Lack of standardization and ubiquity of providers to points of aggregation flows |  | CS1\_DI, Pos. 10 |
| 11 | Clinical data | Provider |  | Physicians assume that the data they look at is incomplete | The absence of ubiquity to be able to share healthcare clinical data | Unnecessary spend and waste: Redundant testing and procedures, misdiagnoses, prolonged suffering | CS1\_DI, Pos. 10 |
| 12 | Prescription data |  | Moderately ubiquitous, well standardized electronic prescribing of medications |  | Serendipity of alignment of stakeholder’s interests: Reduction in expenses by transitioning to electronic prescribing, existing standards, new capabilities, new established workflows, and new system adoption |  | CS1\_DI, Pos. 10 |
| 13 | Data to pay for healthcare and data to treat healthcare |  | Data flow to pay for healthcare and data flow to treat healthcare | The data flow to pay for healthcare is solved for but the data flow to treat healthcare is not | Size of the HC system  “There are in the United States, depending on how you count them, about 350 payers roughly, again, if you throw in all the TPAs [third-party administrators] and other things, it goes closer to 2000. But let’s just say for normal accounting purposes and 350 payers. There are about 7000 hospitals, again, depends on what you call a hospital or not. You can have a more inclusive figure it’ll take you up to about 10,000. There’s about 1.5 million doctors. Now, a lot of these doctors work together, and they have a single practice and a single database system. But still, when you multiply out that many doctors and that many hospitals and that many payers, you quickly come to a place where you’ve got this impossible point-to-point matrix of data. Okay, well, and again, in that impossible point-to-point matrix, we’ve automated the job of paying for healthcare [quote]” |  | CS1\_DI, Pos. 18/397-409 |
| 14 | Claims data |  | Transmission of claims from hospital systems and physicians to HC insurance companies |  |  |  | HINE1\_DI, Pos. 10 |
| 15 | Clinical information |  | Provision of clinical information from hospitals to patients through portals |  |  |  | HINE1\_DI, Pos. 10 |
| 16 | Patient-reported data |  | Provision of patient-reported data to hospitals directly through personal health records |  |  |  | HINE1\_DI, Pos. 10 |
| 17 | Patient-reported outcomes |  | Patient-reported outcomes information from hospitals to pharmaceutical companies and life sciences companies |  |  |  | HINE1\_DI, Pos. 10 |
| 18 | Pharmacy information |  | The transmission of pharmacy information from a pharmaceutical company to a PBM |  |  |  | HINE1\_DI, Pos. 10 |
| 19 |  |  | Aggregation business, where companies pull financial and clinical information from EHRs, payers, and care management information systems, i.e., value-based enablement, population health management, healthcare IT space, pull data from different institutions |  |  | Breaking down the silos | HINE1\_DI, Pos. 10 |
| 20 |  |  |  | Not timely, i.e., there’s a lag on claims and permissions |  |  | HINE1\_DI, Pos. 12 |
| 21 |  |  |  | Not accurate, i.e., there are coding issues (under- and overcoding, i.e., the information registered is not truthful e.g., saying that a patient had a different diagnosis than they actually had, which results in a higher DRG [diagnostic-related group] payment from the payer; including risk adjustment, i.e., saying that a patient is sicker than he his | Fraud and abuse | Waste, e.g., by getting more money from the government to treat the patient | HINE1\_DI, Pos. 12 |
| 22 |  |  |  | Not secure, i.e., patient information is not sufficiently protected | HIPAA and PCI [payment card industry] are not abided by sufficiently rigorously |  | HINE1\_DI, Pos. 12 |
| 23 |  |  |  | Not actionable, i.e., the information shared is not really used to change physicians’ or other stakeholders’ behavior |  |  | HINE1\_DI, Pos. 12 |
| 24 |  |  |  | Data integrity issues | Garbage in (low quality, not timely inputs) leads to garbage out, in particular as when data gets transmitted there is always lost a little bit | Sharing data is of little utility | HINE1\_DI, Pos. 18 |
| 25 | TI/TS (transactional information and transactional statement), including unit-level serialization | All parties along the clinical and commercial pharmaceutical supply chain | Clinical and commercial pharmaceutical supply chain |  |  |  | ETC1\_DI, Pos. 10 |
| 26 | Identity information of customers and suppliers in pharmaceutical (clinical and commercial) supply chain | All parties along the clinical and commercial pharmaceutical supply chain | Clinical and commercial pharmaceutical supply chain | Manufacturer’s do not know who the requesting party is if it is not a customer of their contracted VRS | Manufacturer want to know a requester’s identity to decide whether they respond to a verification request or not | Do not accept verification request messages from VRS | ETC1\_DI, Pos. 14 |
| 27 | Data as coordination mechanism |  |  |  |  | Allows data to be aggregated into a common insight while not giving the data away, i.e., go from the efficiency mechanism for the data being stored and exchanged digitally to the insights | PYV1\_DI, Pos. 4 |
| 28 | Data for analytics and common insight, using AI |  |  |  |  |  | PYV1\_DI, Pos. 4 |
| 29 | Patient outcomes |  | Entity to entity e.g., provider to insurance, provider to provider, not patient to provider, etc. | It is hard to do in an appropriate way |  | Question arises whether it is better to send the data through the patient, i.e., patient mediated data exchange | PYV1\_DI, Pos. 8 |
| 30 | Personally identifiable information |  |  | Digital identity and reachability information problem: Individuals and entities lack user agency in the digital world, i.e., they are dependent on big players having the power over them | There is no patient identifier | Others (big players) have control over them and can deny services | PYV1\_DI, Pos. 10 |
| 31 |  |  |  | [[For context] Digital identity and reachability information problem:] Individuals and entities lack user agency in the digital world, i.e., they are dependent on big players having the power over them | The big health IT vendors have control and power  “But the examples are just step back and watch and just think about what you see, right, what you see is enterprises giving away the keys to their castles without knowing it, right [quote]?” | The software and with that the hosted data is remote controlled by these vendors | PYV1\_DI, Pos. 28 |
| 32 | Personally identifiable information |  |  | Digital identity and reachability information problem: Personal identification vectors are neither unique nor permanent ´ |  | It is expensive to identify the subject over which the data I exchanged and finding each potential EMR operator who might hold data for a person with those PIIs | PYV1\_DI, Pos. 10; PYV1\_DI, Pos. 22-28 |
| 33 | Administrative datasets, e.g., billing, scheduling, insurance, verification |  | Administrative data flows | Easier to automate | More standardized |  | CS2\_DI, Pos. 4 |
| 34 | Clinical datasets, i.e., any patient-specific clinical indicator of health |  | Clinical data flows | Clinical data flows are difficult to create | No standards, i.e., every EHR system out there has a different data model |  | CS2\_DI, Pos. 4 |
| 35 | Clinical datasets, i.e., any patient-specific clinical indicator of health | Health IT vendors | Clinical dataflow | Clinical data flows are difficult to share | Health IT vendors are focused on making their systems the best [status] |  | CS2\_DI, Pos. 6 |
| 36 | Clinical datasets, i.e., any patient-specific clinical indicator of health | Health IT vendors | Clinical dataflow | Clinical data flows are difficult to share | [See Ex\_Data mgmt. and data flows#36] |  | CS2\_DI, Pos. 6 |
| 37 | Clinical datasets, i.e., any patient-specific clinical indicator of health | Health IT vendors | Clinical dataflow | Health IT vendors are focused on getting everyone to use their platform [increase switching costs, have high market share] | The different health IT systems do not talk to each other |  | CS2\_DI, Pos. 6 |
| 38 | Patient data |  |  |  |  |  | ETC\_2\_DI, Pos. 4 |
| 39 | Physician credentialing data |  |  |  |  | It directly affect some of the most important and valuable patient data | ETC\_2\_DI, Pos. 4 |
| 40 |  |  | Data flow about a patient starts with them being born and receiving a birth certificate | This data is collected and indexed in a fairly non-standardized way by all kinds of systems (EHRs, Apple watches, etc.): it is junk, semi-dirty, maybe clean, maybe not siloed |  |  | ETC\_2\_DI\_MAX, Pos. 6 |
| 41 |  |  |  | Health data is centralized | “Health data is like toilet paper. You don’t think about it until you need it and you don’t have it [quote].” |  | ETC\_2\_DI, Pos. 16 |
| 42 | Claims |  |  |  |  |  | PY2\_DI, Pos. 6 |
| 43 | Clinical data |  |  |  |  |  | PY2\_DI, Pos. 6 |
| 44 | Administrative data |  | Electronic data interchange |  |  |  | PY2\_DI, Pos. 8 |
| 45 |  |  | Health information exchanges including the admissions and discharges and transfers (ADTs) |  |  |  | PY2\_DI, Pos. 8 |
| 46 |  |  | The standard determinants of health (SDOH): Data points about how the local community is doing in terms of healthcare provision |  |  |  | PY2\_DI, Pos. 8 |
| 47 |  |  |  | Siloed nature of the data | “So, it’s kind of like you don’t have the roads, right? Like there’s a bunch of garages with cars, but there’s no roads, and so everybody’s building their own roads to try to like to connect stuff. But there’s no, like, central, like, we have an interstate, right, or any of those type things to help with the utility of everybody being able to use the same infrastructure [quote].” | [See Ex\_Data mgmt. and data flows#49] | PY2\_DI, Pos. 10-14 |
| 48 |  |  |  | Breadth and depth of data |  | [See Ex\_Data mgmt. and data flows#49] | PY2\_DI, Pos. 10-14 |
| 49 |  |  |  | HC system lacks a utility function to provide connectivity between siloed data serving as a single registry. | No one has enough money, knowledge, resources, or desire to build something that meets the needs of everyone | [See Ex\_Data mgmt. and data flows#50] | PY2\_DI, Pos. 12-16 |
| 50 |  |  |  | There are many individual point to point solutions |  | This duplication results in cost to the patient | PY2\_DI, Pos. 12-16 |
| 51 | Real-world evidence | Manufacturer |  |  |  |  | M1\_DI, Pos. 6 |
| 52 | Diagnostic data, i.e., used as lead data generator to send the sales force to the physician and promote the product for the patient | Manufacturer |  |  |  |  | M1\_DI, Pos. 6 |
| 53 | Patient-journey/patient experience data through pharmacies, i.e., used as lead data generator to send the sales force to the physician and promote the product for the patient | Manufacturer |  |  |  |  | M1\_DI, Pos. 6 |
| 54 | Present |  | Patient lifecycle: From ailment discussion to lab diagnosis tests with the data to be purchased de-identified by manufacturers to product selection by physician and reimbursement process initiation to product purchasing in pharmacies whose data is bought by manufacturers and treatment |  |  |  | M1\_DI, Pos. 8 |
| 55 | EMRs | Providers, manufacturers | Sharing of EHRs and their data with all kind of shareholders (providers for drug decision, manufacturers for understanding treatment patterns) |  |  |  | M2\_DI, Pos. 8 |
| 56 | Claims data | Payers, manufacturers, | Plugging into claims data to understand market share and the pros and cons of a drug (price, length of treatment, etc.,) |  |  |  | M2\_DI, Pos. 8 |
| 57 | SEER\_Medicare (a Medicare database) | Federal agencies, manufacturer |  |  |  |  | M2\_DI, Pos. 8-10 |
| 58 | Real world data registries and databases | Manufacturers, other countries | Manufacturers plug into those to understand how much people are being tested and whether targeted treatments are being used to gain insights into what the remaining unmet need might be, and how they stack up versus competition |  |  |  | M2\_DI, Pos. 10 |
| 59 | Research data |  |  |  |  |  | HINE2\_DI, Pos. 6 |
| 60 | Clinical data, including lab data |  |  |  |  |  | HINE2\_DI, Pos. 6 |
| 61 | Payer data |  |  |  |  |  | HINE2\_DI, Pos. 6 |
| 62 |  |  |  | How do you aggregate across all these disparate data sources? i.e., How do you gather all that longitudinal information to treat a patient or to better their health/improve their outcomes [see screenshot] |  |  | HINE2\_DI, Pos. 21 |
| 63 | Visit level data, i.e., a list of appointments the patient had | Provider, i.e., all kind of data when it is first created starts in the provider system |  | Systems do not talk to each other very much |  |  | HITV1\_DI, Pos. 2 |
| 64 | Patient care data | Provider, i.e., all kind of data when it is first created starts in the provider system |  | Systems do not talk to each other very much |  |  | HITV1\_DI, Pos. 2 |
| 65 | Claims data | Providers, payers |  | Systems do not talk to each other very much |  |  | HITV1\_DI, Pos. 2 |
| 66 | Data the health IT system’s actual functionality allows health IT vendors to collect (patient data, appointments, billing, etc.) | Health IT vendors |  | There is a lot of variation in the data collected from provider to provider | The EMRs are adaptable and configured to the clients wishes | Even if parties wanted to share information it is not as rich and useful, i.e., a PDF copy of a report vs actual discrete information | HITV1\_DI, Pos. 4 |
| 67 | Where is the data stored and who owns it? | Health IT vendors | Health IT vendors leverage data sharing agreements to use the data for analytical purposes | Health IT vendor employees can access freely any amount of data | “(…) it’s almost like [health IT vendor] has a little virus within every healthcare system that it works in and if it wanted to just suck everything out, it could really at any moment, even though it’s like the healthcare system that owns it (…) [quote].” | It makes the question about who has access and owns the data hairy | HITV1\_DI, Pos. 4-6 |
| 68 |  | Health IT vendors | Systems need to interoperate from one health IT system to another health IT system e.g., Epic to Cerner | Health IT vendors are disincentivized to interoperate / No health IT vendor wants to be the first to make the systems interoperable | Health IT vendors worry about providers switching systems and them losing access to all of the data | Little attempt of cooperation between major health IT vendors | HITV1\_DI, Pos. 8 |
| 69 |  | Health IT vendors, providers | Systems need to interoperate from provider to provider | Challenge of making interoperability scale when every health system does something differently | Providers have different organizational preferences | Only the most basic information that does not help with more advanced treatment plans gets shared directly and not via PDF records that no one looks at | HITV1\_DI, Pos. 8 |
| 70 |  |  |  | Patient matching can be inaccurate |  | Data quality issues | PV2\_HINE3\_DI, Pos. 4 |
| 71 |  |  |  | Data is not complete |  | Data quality issues | PV2\_HINE3\_DI, Pos. 4 |
| 72 |  |  |  | Data is not usable | Data is not stored in appropriate fields to have the right metadata | Data quality issues | PV2\_HINE3\_DI, Pos. 4 |
| 73 |  | Centralized data exchanges, such as HIEs, HIOs, health data utility |  | Honeypot for hackers |  |  | PV2\_HINE3\_DI, Pos. 4 |
| 74 |  | Centralized data exchanges, such as HIEs, HIOs, health data utility |  | If you have lots of local systems, 10s of 1000s of them around the world, how do they remain standardized? How do they exchange with one another? How does a patient collect all of their information, i.e., which regions do they need to check? |  |  | PV2\_HINE3\_DI, Pos. 4 |
| 75 |  | Providers | Provider-provider exchange to support treatment (largest volume) |  |  |  | PV2\_HINE3\_DI, Pos. 10 |
| 76 |  | Providers, payers | Provider to payer to get paid (bi-directional: There are queries about coverage, adjudicating claims, prior-authorization) audio quality measures) |  |  |  | PV2\_HINE3\_DI, Pos. 10 |
| 77 |  | Providers, public health | Public health exchange (mostly uni-directional: case reporting, reporting to registries, electronic laboratory reporting, syndromic surveillance) |  |  |  | PV2\_HINE3\_DI, Pos. 10 |
| 78 |  | Patients, providers | Patients getting data from their providers |  |  |  | PV2\_HINE3\_DI, Pos. 10 |
| 79 |  |  |  | Data blocking, i.e., those that have the data are not willing to share it | Data siloing | Data remains locked in silos, unavailable for clinical or individual use, public health access for researchers | PV2\_HINE3\_DI, Pos. 12 |
| 80 |  | Providers, payers |  | Data blocking, i.e., those that have the data are not willing to share it | The penalties/disincentives for providers information blocking have not been defined yet in policy |  | PV2\_HINE3\_DI, Pos. 12 |
| 81 |  |  |  | Structure of the rules cause problems, i.e., information blocking prohibitions do not apply to payers but only certified health IT developers, HIEs, providers [leaving out some stakeholders from regulations causes issues] | Tapestry of self-interests and confusion on part of stakeholders and data holders | Payers engage in information blocking | PV2\_HINE3\_DI, Pos. 12 |
| 82 |  |  |  | Consent processes: Who are you, what purpose are you requesting the data for, e.g., treatment purposes, payment healthcare operations, public health exchange, benefits determination, applying for life insurance, signed an authorization to be involved in a research study? Each purpose of use has a different legal structure around access |  | Tapestry of rules, regulations, requirements, restrictions, confusion on part of stakeholders and data holders | PV2\_HINE3\_DI, Pos. 12 |
| 83 |  |  |  | Different patterns of exchange are supported by different technologies |  | It is hard to always invest in the technology changes to bring people up to a new standard | PV2\_HINE3\_DI, Pos. 15 |
| 84 |  |  |  | Data right issues: Who owns the data? Who controls the data? Who can monetize the data? Who has to pay to get access to the data? |  |  | PV2\_HINE3\_DI, Pos. 18 |
| 85 |  | Federal agencies | From a federal agencies’ perspective, look at the data sources/origin points of data and, where does it flow from there and which federal agency might have a regulatory role |  |  |  | FA1\_DI, Pos. 4 |