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Health Information Sharing and Exclusion in the Age of COVID-19 (Georgia State, 5/26)

Aaron Baird and William Olivera, Georgia State University

Abstract

Contact: Aaron M. Baird abaird@gsu.edu

What is the message: The spread of COVID-19 might be significantly reduced if more health care organizations were willing and able to share essential information about cases and treatments. However, health information sharing often occurs between members of "clubs," such as only between health care providers connected to dedicated health information exchanges or only between hospitals and firms with information sharing agreements. Club goods, such as health information, are both non-rivalrous and excludable. In the case of health information sharing, especially during a pandemic, better outcomes might be achieved if health information exclusion was reduced; especially when public health agencies need case reports for making intervention decisions. Interestingly, though, even when hospitals want to share COVID-19 case and treatment information with public health agencies and other health care entities, such sharing requires either pre-established interfaces, such as application programming interfaces (APIs) or some sort of system that supports manual or batched transmission of data. Further, club theory does not fully explain how a good can transition from more exclusive to a less exclusive public good during unique times of need. To address these issues, we propose two mechanisms—health information rights flexibility and club coordination—that can be leveraged both prior to and during pandemics to reduce health information exclusion.

What is the evidence: The authors draw on experience in health information technology and club theory as well as recent articles on COVID-19 information sharing practices.

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Health Information is Valuable but Difficult to Share

The U.S. Centers for Disease Control (CDC) is in the early stages of offering a COVID-19 electronic case reporting application. This application is meant to help health care providers more easily connect to public health agencies and submit reports of potential COVID-19 cases.[1] But, with all of the investment into electronic health records (EHRs) by health care providers, why is this electronic case reporting application even needed in the first place?

The reason is that health information is not shared as readily as it should be in the U.S. due to a variety of technical, competitive, and political issues. Health care is fundamentally a market for information, and information is excludable.[1,2] In particular, rights to information are often retained, or at least managed, by the entity collecting and storing the information. In the case of health care, patient health information is typically collected and stored by health care providers and associated ancillaries such as laboratories, imaging centers, and pharmacies.[3] While patients may retain the right to access this information, as afforded by the Health Insurance Portability and Accountability Act,[4] health information often is difficult to share.

For instance, many cases of information blocking have led the U.S. to pass additional provisions focused on enhancing health information interoperability and penalizing purposeful blocking of authorized exchange.[5,6] Further, it has been reported that connecting to public health agencies can be especially challenging during this pandemic due to barriers such as lack of interfaces available from such agencies.[7] What is particularly troubling, especially during a pandemic, is that barriers to health information sharing can delay possible treatments, lengthen economically draining quarantines, and cost lives.

An ideal scenario, as described in other opinion papers,[8] would be a national health IT infrastructure that houses accurate and reliable public and population health data. This type of approach could give the U.S. a readily available source to track and trace individuals showing COVID-19 symptoms or testing positive.[9,10] However, the lack of a unique national patient identifier and the reluctance of health care organizations to participate, as well as political and technical challenges, are immediate barriers for adoption for such infrastructure.[11]

Limits to Current Information Exchange Standards

To overcome such barriers, health care stakeholders have been working to develop a modern health information exchange standard. The result of these efforts is a standard referred to as Fast Healthcare Interoperability Resources (FHIR). While considered with skepticism early on, especially due to the relative recency of the HL7 v3 debacle,[12] FHIR has rapidly evolved and become one of health care's best hopes for addressing many of the challenges associated with sharing health information. In fact, the positive momentum has resulted in the U.S. Office of the National Coordinator of Health Information Technology mandating the adoption of FHIR HL7 v4 by spring of 2022 for all health care providers.[13] Many health IT vendors are now building FHIR support into their products, and many health organizations are beginning to use FHIR to exchange information and support health applications.[14-16]

However, not all EHR and health information systems enable FHIR-based APIs in their products and not all health information exchange use cases have been fully accounted for. For instance, FHIR-based electronic case reporting will reportedly be enabled by the CDC's application we mentioned earlier. Reporting COVID-19 cases via such FHIR-based interfaces requires that the health care provider already have FHIR-based APIs available and enabled within their EHR. It also requires that rules be established by the health care provider for which data should trigger case reports and which data should be collected and transferred when seeking to report positive or suspected COVID-19 cases. Further, even with the availability of the COVID-19 electronic case reporting application from the CDC, it is still thought that electronic case reporting and contact tracing will remain highly variable.[17-19] For instance, underprivileged areas with limited technological resources may need to rely on other forms of reporting.[2]

Thus, health information sharing is not frictionless. Pandemics can further exacerbate such frictions, as even less resources are typically available for improving or even improvising required rules, agreements, and interfacing. As has been well documented over the past several years, digitizing health information is only part of the challenge.[20] The subsequent and perhaps more consequential challenge is using digital health information, often obtained and aggregated from multiple health care providers, to improve overall health and health care.[21-25]

Given these current limits, the goal of this paper to critically assess health information sharing, particularly from the perspective of reducing exclusion during a pandemic.

In the next section, we provide more detail about how club theory applies to health information sharing. In the following sections, we propose what we term transitional mechanisms that can be applied by academics and practitioners when considering how to best transition health information from a club good to more of a public good during a pandemic, and potentially back to a club good post-pandemic. We also consider how these transitional mechanisms can be applied in practice, especially during the following stages of a pandemic: 1) early detection and investigation, 2) comprehensive assessment, and 3) monitoring.[26]

Insights from Club Theory

Health information is a club good

We consider health information to be a club good or quasi-public good in that it is both non-rivalrous and excludable. That is, consumption by one entity does not prevent consumption by another entity, yet sharing can be prevented, and benefits can be monopolized or restricted to members of a club.[3,27-29]

Club theory considers goods that are not entirely private or public. It often focuses on explaining how membership costs of joining clubs, potential congestion within clubs, rivalries between clubs, and externalities generated by clubs impact resource use and outcomes.[28,30,31] Members join the club to reduce production costs or impose exclusion on a good, or both, but also must consider congestion as too many members may result in negative externalities.[28,30,31] Thus,

membership in clubs is often limited to the number of people for which benefits can be generated without excessive congestion.

Rival health information clubs have long faced barriers to exchange

Due to such membership limitations, clubs can be rivals in that the capabilities of each club vary, and competition for network effects creates competition between clubs. Further, given that the capabilities of each club vary, attracting members requires differentiated value propositions,[32] meaning that health information market partitioning is a regular practice by such clubs. For example, club members can exchange health information using automated FHIR-based interfaces (i.e., APIs for structured data) or secure email exchange of records as PDFs (i.e., unstructured data that is difficult to query or aggregate) depending on their technological capabilities.[33]

These health information sharing clubs can include state-level health information exchanges; public health information interfaces, including CDC's new case reporting app for COVID-19; and even exclusive partnerships with private companies such as Apple, Google, or Epic that share information between participants. However, sharing between such clubs requires deliberate efforts.

While it might be easy to argue that membership costs for health information sharing are gradually being reduced and heading toward much lower marginal costs, many years of work in improving health information sharing capabilities have not reduced the marginal costs to anywhere near zero. While these costs might be much lower in the future, currently the cost of interfacing remains a barrier. Further, membership costs may also include fees that at least cover the overhead of the club.

Membership costs, even if declining, are unavoidable, and market partitioning happens regularly. Further, health information has never been entirely treated as public good in order to protect patient privacy. Simply releasing all information into the public domain is also not an option.

We expect membership costs for joining health information sharing clubs to be present into the foreseeable future. This means that the excludability characteristic of health information is not

simply going to disappear over time.

The essential question then becomes, *what can be done prior to and during a pandemic to reduce health information excludability*, *thereby enhancing the potential for health information sharing?*

Current suggestions for information exchange during a pandemic are inadequate

The most obvious answer is to make accommodations or even improvisations that relax health information exclusions and shift health information more toward a public good, especially during a pandemic. While the privacy of identifiable patient information prevents full public disclosure, health information rights can be customized to meet public health needs. For instance, one might send only COVID-19 case reports to public health agencies rather than records for all patients irrespective of diagnosis or symptoms.

While making such accommodations and even improvisations makes intuitive sense, in practice there are formidable challenges associated with fragmented health information and varying needs for accessing this information. As an example of this challenge, consider how a health care provider should determine whether or not to flag a case as a potential COVID-19 case.[34,35] Should the record be flagged as reportable only if a positive test is obtained? If testing is not available, is inconclusive, or is delayed, are there particular symptoms, lab test values, or observables that should then be leveraged to make a potentially positive or negative case decision? Further, which entities should be making the final decisions as to what benchmarks that subjective or ambiguous data should reach prior to arriving at the judgment for a case?

As a consequence of such decision making, one solution would simply be to send all even suspected cases to local public health agencies. Unless such agencies have substantial resources, however, too much information on too many patients will not be helpful and may overwhelm available resources.

As opposed to over-reporting, under-reporting is also a significant risk, as too little information may exacerbate the spread or delay potential investigations required to facilitate contact tracing. Further, fragmented information, especially if a patient has visited multiple providers or has provided incomplete information such as incomplete travel history may complicate the

efforts that need to be taken by agencies receiving such information.

In sum, while we propose that health information should be less excludable during a pandemic, club theory currently does not provide an answer into how to make exclusion transitions during and even after pandemics. Concepts such as membership costs, rivalries, and externalities provide an excellent framing,[28,30,31] and we have seen models that attempt to capture the complexity of infectious diseases using a loose coupling framework.[36] What is missing, though, are the mechanisms by which health information excludability could be reduced in a crisis.

Transitional Mechanisms: Rights Flexibility and Club Coordination

To address this theoretical and practical challenge, we propose two mechanisms related to supporting and enabling reductions in health information exclusion during pandemics: 1) rights flexibility, and 2) club coordination. We view these mechanisms as transitional in that they can help to shift from health information exclusiveness in a pre-pandemic time period to more sharing during a pandemic response. Further, they can also aid in returning exclusion restrictions to pre-pandemic levels once a pandemic has passed or stabilized.

Health information rights flexibility

Health information rights are the ownership of or entitlement to health information.[3,4,37] Health information rights flexibility would be the ability to flexibly change ownership rules and entitlement requirements associated with health information during a time of need or crisis. Exclusive rights to health information lie on one end of the continuum of private and club goods, while non-exclusive rights to public goods lie on the other end of the continuum.

***Information ownership during normal times*:** Pre-pandemic, rights tend to be exclusive. In fact, it would not even be known in a pre-pandemic time period which health information other entities would need rights to, as the nature of a future virus would unknown.

Flexibility during a pandemic: During a pandemic, more information becomes available about the virus, associated symptoms and markers or relevant diagnostics, and potential treatments. In turn, relevant categories of health information can be identified as needed by

public health agencies and organizations doing disease and treatment research and development. These categories of information can thus be classified as requiring less exclusions. Rights can then be distributed to the entities requiring access.

***EHR design*:** It is easy enough for a government or regulatory agency to temporarily change rights to health information, such as by saying that all COVID-19 cases must be reported to public health agencies,[3] thereby loosening the exclusive hold on such data by health care providers. However, it is much more difficult to quickly change health information systems, such as EHRs, to abide by such new regulations. Thus, we propose that rights flexibility be designed directly into health information systems, such as EHRs and data warehouses maintained by health care providers and health information sharing clubs.

***Limits to date*:** Some efforts have been made in this regard by public health agencies, such as with the Reportable Conditions Knowledge Management System being rolled out by the CDC as well as use of the National Health Safety Network for consolidating case reporting.[4] However, real-time or near real-time linking and coordinating of dynamic health information access rules within and between health care providers, public health agencies, and other stakeholders has not been a priority.

***Opportunities for rules engines*:** We propose that health information systems be modified to incorporate rules engines that define health information rights with respect to conditions that may require more access, such as COVID-19. Such rules engines should support rapid modification of health information rights at a granular level, with detail at least per condition, and potentially by groups of symptoms and diagnostic values. The rules engines also require dynamic updating of interfaces, such as with public health agencies and other relevant health information clubs, that need access to such information.

Health information club coordination

We also propose club coordination as an essential mechanism for transitioning toward less health information exclusion during a pandemic. Coordination traditionally focuses on two activities: “managing dependencies between activities;” [38] and “the process of interaction that integrates a collective set of independent tasks,” including conditions of accountability,

predictability, and common understanding.[39]

Coordination between clubs: Because coordination typically occurs within health information clubs, as this is the purpose of the club, the primary challenge during a pandemic is coordinating between clubs. A key challenge is that health information is not homogenous between clubs, as information is shared in more or less granularity depending on the nature of the club or may even be transformed in different ways depending on the nature of the club.

For instance, claims data payment information may be shared with insurance companies and payers such as the Centers for Medicare and Medicaid Services, but such claims data does not include granular clinical data required for deeply investigating a case. Nonetheless, such claims data does provide information about diagnoses and procedures and could be useful in assessing treatment variation for a specific diagnosis. Given the heterogeneous nature of health information, as well as potential rivalries between often competing clubs and coordination of data often required when assessing causes and effects in pandemics, we propose club coordination as an essential pandemic mechanism.

Data dictionaries: In particular, we propose that health information clubs be required to maintain data dictionaries in pre-pandemic time periods, or rapidly develop such data dictionaries during a pandemic. These data dictionaries can then be accessed by public health agencies and other relevant stakeholders, without compromising security or privacy, when seeking to determine which health information fields, formats, and transformations are immediately available for data collection and analysis.

We further propose that during a pandemic, health information clubs be required to identify areas of overlap or uniqueness between their data dictionary and data dictionaries of other health information clubs that report to the same public health agencies or stakeholders. For instance, health information club A might have patient travel data while health information club B does not have this data but has other relevant clinical data such as essential lab test results. In such a case, knowledge of which data is unique and which is common to other clubs will help relevant agencies quickly identify which health information to request from each club.

In this way, interdependencies between clubs can be identified rapidly. Knowledge of the linkages can help reduce coordination and congestion costs for public health agencies and other

stakeholders in need of the information.

Aligning the Transitional Mechanisms with Pandemic Stages

We now briefly consider how to align these two mechanisms with the three stages of pandemic surveillance proposed by the World Health Organization: (1) early detection and investigation, (2) comprehensive assessment, and (3) monitoring (Table 1).[26]

Table 1. Transitional mechanisms at each pandemic surveillance stage

Pandemic Surveillance Stage	Rights flexibility	Club coordination
Stage 1: Early Detection and Investigation	· Rules engines should be updated to trigger electronic case reports for cases with positive tests as well as for cases where symptoms or diagnostics are a sufficient match to warrant a case report. · Public health agency capacity for electronic case report transmission and receipt should be verified. If sufficient or excess capacity is available, triggers for electronic case reports might be set to err on the side of caution and potentially over-report rather than risk under-reporting.	· Health information clubs must provide data dictionaries to public health agencies. · Preferably, overlaps with other health information clubs; instances of unique data, such as patient travel data, should also be identified.
Stage 2: Comprehensive Assessment	· Evaluation of the rules triggering case reports should occur. If under-reporting or over-reporting is occurring or cases are being missed or incorrectly identified, rules should be revised as needed. Ideally, such revisions would be based on rules from an authoritative source, such as the CDC. · Evaluation of missing population data should also occur. The goal should be to determine sources for reach extracting accurate and reliable information.	· Opportunities for improved data sharing should be explored. Are there other sources of data that could be explored? Is sufficient data be shared between members and public health agencies? · Update the EHR or source of health data with any new fields and standardized terminology or codes needed, such as updated ICD-10, CPT, or LOINC codes.
Stage 3: Monitoring	· Implement processes and procedures that audit and reconcile the numbers of case reports occurring within the health care system with the number being reported to public health agencies. Discrepancies should be addressed through rules revisions. · Create guidelines to address how to handle data collection privacy during the pandemic as well as once the pandemic starts to recede.	· Reconciliation of case reporting numbers should also occur between a health system and the health information clubs it is part of. · Health information clubs should discuss with their members the efficiency of the data collected. They should coordinate to determine the best process to efficiently capture, store, and share reliable data moving forward.

Pandemic surveillance stage 1: Early detection and investigation

During the first stages of pandemic surveillance, involving early detection and investigation, the goal is to detect human-to-human transmission, characterize the features of the new disease, and define high-risk groups to prioritize interventions.[26] Time is critical during these initial stages, particularly when assessing the magnitude of the new disease.

From a rights flexibility perspective, we propose that during this initial stage, health information systems need to have rules engines that can quickly adjust information rights corresponding to the health information needed to assess disease magnitude and infection rates. In cases where no standard interface with one or more public health agencies has yet to be established, health information sharing clubs would be asked to manually share required health information to enable rapid response and avoid evaluation delays.[40-42] This would be an incentive to rapidly invest in interfaces or to have such interfaces developed in advance of a pandemic.

An issue, however, may be that public health agencies may lack the proper technology infrastructure to receive and evaluate electronic case reports, especially at high volumes.[7] Therefore, during this initial stage, public health agencies should evaluate their capacity and bandwidth to receive electronic case reports. If insufficient capacity is available, electronic case reports should be set to be conservatively triggered, such as only when a positive test is received for a case. Such an approach will help avoid confestion and cognitive overload issues at the public health agency. If on the other hand sufficient capacity is available, triggers on electronic case reports can be set to report more liberally, such as not only when positive tests occur but also when symptoms are consistent with having the disease.

From a club coordination perspective, while we have proposed that health information clubs maintain data dictionaries in pre-pandemic periods, we also suggest clubs communicate with each other during this stage, to determine health information overlaps and gaps between them. The goal of this exercise is for health information clubs to take an active role in determining which clubs will be the most reliable combined sources of information for public health agencies and other relevant stakeholders.

Pandemic surveillance stage 2: Comprehensive assessment

During the comprehensive assessment stage of a pandemic, the goal is to facilitate more effective responses at both national and international levels. Public health agencies will need to characterize the epidemiological features of the outbreak, such as the distribution of cases and deaths by age group, describe the impact of the illness on the community, and define transmission characteristics, such as incubation period and epidemiological curve.[26]

From a rights flexibility perspective, we recommend evaluating the rule engines based on the early assessment from authoritative sources, such as the CDC. At this point, public health agencies should be able to determine if they are missing health data or if there is an inconsistent overlap of data. Rule engines will need to be correspondingly updated as knowledge about disease transmission and progression evolves.

At the same time, public health agencies can also look at the patient population not included in the electronic case reports, which may not be included in the tracked by interfaced health information clubs. This information should be shared with relevant health information clubs that should subsequently determine what health facilities, stakeholder, or technology applications are in the best position to collect the needed information on the missing population.

From a club coordination perspective, in this stage health information clubs should evaluate opportunities to improve data sharing. They should evaluate what other sources of data could be explored or may be beneficial to share with public health agencies. At the same time, EHR or health applications that are sources of essential information should be updated based on the latest field recommendations from public health authorities. For example, during COVID-19, the CDC released new data entry codes (e.g., ICD-10, CPT, and LOINC) to capture pandemic related data. The new codes, as well as standardizing naming conventions across applications within clubs, can help facilitate improve needed health information collection, aggregation, and analysis.[17]

Pandemic surveillance stage 3: Monitoring

As the pandemic moves to the monitoring stage, public health agency information needs may be more standardized rather than exploratory, as more is now known about what should trigger an electronic case report and what symptoms should be tracked over time.[43] Once public health

agencies have a better understanding of the disease, they are likely to suggest additional or more standardized guidelines that help transition pandemic surveillance to monitoring. Under monitoring, public health agencies track the disease in terms of geographical spread, intensity, and impact. It is also essential to highlight and look for cases that fall outside of typical, known patterns. At this stage, health information clubs should prioritize the accuracy and reliability of information over volume.

In terms of rights flexibility, health systems should implement procedures and processes to reconcile the number of case reports occurring within the health care system in relation to the number of cases being reported to public health agencies. The procedures should provide direction to improve patient matching and leverage additional fields such as demographic data and, if available, relevant social and genetic data. At the same time, health care organizations should create guidelines to address the patient privacy of newly required fields as well as how to handle ongoing data collection as the pandemic moves to a more stable period, such as by creating sunset clauses on data collection trace applications.[44]

From a club coordination perspective, electronic case reporting reconciliation should occur between individual health systems and the health information club they are a part of. Health information clubs can also discuss with their members the efficiency of the data collected and determine additional best process to efficiently capture, store, and share reliable data. For example, they can determine the best health entity, stakeholder, or technological application to capture reliable and accurate data. At the same time, they can determine fields that are not useful to capture or are redundant between the health information clubs. Finally, after a systematic assessment of fields, they should update data dictionaries within the clubs.

Looking Forward

We have identified that sharing health information is essential to pandemic responsiveness. Using ideas from club theory, we have analyzed the challenges associated with information exclusion by health information sharing clubs during a pandemic. We propose that reducing health information rights exclusion is necessary during a pandemic while highlighting current difficulties in achieving this goal.

We propose two mechanisms that can achieve greater information sharing during a pandemic:

rights flexibility and club coordination. When paired with specific modifications to health information systems as recommended in this paper, including incorporating rights engines and and keep up-to-date data dictionaries, these mechanisms can accelerate health information exchange pre-, during, and post-pandemic.

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[1] Please see https://www.healthcaredive.com/news/cdc-to-launch-clinical-reporting-app-for-covid-19-in-may/576129/ for more details.

[2] e.g., https://ehrintelligence.com/news/key-piece-to-todays-interoperability-puzzle-cloud-fax

[3] e.g., https://www.cdc.gov/coronavirus/2019-ncov/php/reporting-pui.html

[4] Please see https://www.cdc.gov/ehrmeaningfuluse/Reportable-Conditions-Knowledge-Management-System.html and https://www.cdc.gov/nhsn/index.html for more details.