



## Call for Action

Data sources with electronic exchange must transmit data electronically with PHRs

### Summary

Peoplechart works on behalf of consumers to collect, organize, and securely distribute their medical records so that the information is both secure and available when needed to health providers and other authorized individuals.

One of the most challenging and costly components of this effort is converting paper-based records into a more secure, easier-to-share digital format. We have found that most large health information systems have the ability to provide patient data in electronic format, and many can share this data with other provider-owned EMR systems using industry-standards for transmittal.

Some PHRs, like Peoplechart, have developed the ability to exchange patient's health data electronically on behalf of consumers. However, the health information industry and recent public initiatives have not made an explicit call to include PHRs in the implementation efforts for electronic data exchange. Even providers with capabilities in place to upload and share patient files electronically still insist on sending paper copies to PHRs that request electronic data on behalf of consumers.

The issue is lack of willingness or incentives on the part of health care providers to share data electronically with consumers and the PHRs working on consumers' behalf. The result is unnecessarily high costs of photocopying and managing the medical records that must be absorbed, usually by consumers. To continue adding value for consumers, PHRs must be given the same opportunity as EMRs and RHIOs to access and share electronic patient data. To the extent that the provider and the PHR have the systems infrastructure in place for exchanging data, then electronic transmittal should be the requirement and general practice.

### **Electronic Data Sharing Capabilities Exist Today**

Peoplechart has found that most established health systems have the capabilities in place for data exchange with hospital-run EMR systems. With very minimal set-up costs, these ‘capable’ systems could facilitate data exchanges with PHRs that are interested in capturing electronic data on behalf of consumers.

Over the past few years, we have attended a number of medical informatics conferences. Thus far, the topics on data exchange have been focused almost entirely on interoperability across health provider systems (EMRs or EHRs). The PHR provides a strong technological and service solution for consumers who want to store and manage information about their health. Our ability to deliver real value to consumers is currently hindered by the fact that PHRs are not given the same opportunities as provider-based systems to capture patient’s health information in electronic format.

### **Failure to Include PHRs in Interoperability Projects Discourages Consumer Involvement and Increases Costs**

With interoperability efforts underway for provider information systems, the public sector can help consumers leverage the progress that has been made in the areas of data standardization and infrastructure for electronic data sharing. By requiring EHRs and other source systems with electronic file upload capabilities to work with patient-managed PHRs that also have similar capabilities, PHRs can—at the patient’s request—access the same electronic patient data that is being shared between provider-based EHRs.

This means providing adequate public focus and oversight—like incentives, legislative policies, and certifications – for ‘capable’ source systems (those that have implemented standards-based transmittal capabilities, such as diagnostic labs, pharmacies, hospitals, health plans, and government medical organizations) to exchange data electronically with PHRs whenever the patient requests an electronic copy of their records. This may require further clarification of the national regulations in place today for enabling patient access to copies of their medical records.

By failing to agree to share data electronically with consumers or their PHRs, providers are unnecessarily increasing the costs of maintaining and managing health information for consumers. Paper-based records are more labor intensive and expensive to manage and transmit than electronic ones.

### **Our Experience**

As a pioneer in the area of consumer empowerment, Peoplechart has developed an integration engine that, at the request of the patient, can capture, translate, and map personal health data in HL7 format to XML and other commonly used electronic formats. Yet, there is a lack of policy and infrastructure in place to support electronic data exchange between provider source systems and consumer-managed PHRs like Peoplechart.

The following is a brief overview of Peoplechart’s experience to date with various electronic health record source systems:

## **Diagnostic Labs**

We have been able to develop the integration capabilities for the electronic capture of diagnostic lab results in any HL7 or XML format. However, to actually receive, store, and validate data has been a journey of one-on-one relationships with the source organizations, each relationship and data exchange process must be developed individually and cultivated over time.

## **Medication History**

At first glance, electronic exchange of medication data seems easier because of the existence of a network infrastructure that enables data exchange based on industry standards and guides. But in reality, this network is dominated by a small handful of data managers/processors in the industry.

To date, there have been no public oversight or enforcements on how these players must work with PHRs. As a result, the same patient data files currently being sent to EHRs or physicians electronically are not being shared with PHRs electronically. Requests for medical record copies by PHRs on behalf of consumers are almost always shared only in paper format.

We believe that the incremental effort behind provider systems that currently share patient data with other provider systems to share patient data with PHRs can be implemented with minimal changes. With some tailoring to acknowledge that it's an individual patient (versus provider request), the same infrastructure for data format, file type, and processes could be used in response to PHR request.

It seems that the data organizations have responded to our requests for implementation (and certification) of electronic data sharing based on their own schedules, and have little incentive to make data sharing with PHRs a priority.

## **RHIOs (Large Hospital Systems)**

We have approached a number of large RHIOs about including PHRs in their plans for electronic data exchange, and the response has been that "PHRs are important, but we have had too much on our plate right now (networks for EMRs, security, and privacy issues) that need our attention. We cannot consider PHRs at this time. Contact us again in a few months."

## **CALL FOR ACTION**

We have found that most health systems have the capabilities in place for data exchange with hospital-run EMR systems. With very minimal set-up costs, these 'capable' systems could facilitate the same type of data exchanges with PHRs that are interested in capturing electronic data on behalf of patients.

### **Short Term Recommendations:**

There is a need for public-sector oversight to ensure that there is willingness on the part of 'capable' source systems (those that have file transfer or transmittal infrastructure in place to send data using industry-based standards) to exchange data electronically with PHRs. This means that the public entity:

- Leverages current government-sponsored or funded interoperable projects to explicitly include participation by PHRs

- Provides a public list of these ‘capable’ source system entities as part of disclosure and transparency
- Reviews ways to promote or motivate provider source systems to leverage current EMR data exchange infrastructure with PHR
- Ensures that the source systems (labs, pharmacies, and hospitals) set up a patient identification code, like a Medical Record Number or Master Patient Index, so that the PHR (like EMRs) can retrieve data for only that patient
- Facilitates easier data access by requiring patient file upload with strong encryption be placed outside the firewall (similar to current practice at diagnostic labs and EMRs).
- Leverages and promotes the use of off-the-shelf or open source encryption software for securing data exchange
- Educates provider source systems on the importance and tangible benefits for patients in having an electronic copy of the clinical records for reducing liabilities and overall costs

**Long Term Recommendations:**

We consider PHRs to be a strong complement (not replacement) for EMR systems. PHRs have strong obligation as patient advocate and an advantage in terms of privacy of patient-initiated requests.

To the extent possible, PHRs should be certified in terms of various industry standards-based requirements, such as privacy, security, and interoperability.

PHRs can add a great deal of informational value to the quality of care delivered by providers and to the robustness of data stored in provider systems. To continue building on our value to consumers, PHRs must also be given the same opportunity—in public resources and enforcements—as EMRs and RHIOs to access and share electronic patient data.