



Version	Approval Date	Owner
1.1	11/14/18	Innovation, Research, & Development

Consumers’ Right to Direct and Control Transmission of Their Personal Data via HSX MarketStreet

1. Purpose

The *Consumers Right to Direct and Control Transmission of Their Personal Data Use Case* (the “**Consumer Use Case**”) governs the procedures for allowing HealthShare Exchange (HSX) to enable Consumers to direct and control transmission of their personal Data from HSX’s clinical databases and to share such information through HSX MarketStreet Application Programming Interfaces (APIs) using a secure medium chosen by the Consumer. Enabling a Consumer’s ability to direct and control their personal Data, including their healthcare information, can positively influence patient-centered care, especially through enhancing communications between patients and their providers.

The *21st Century Cures Act* and the Centers for Medicaid & Medicare Services’ *Meaningful Use Stage 3 Patient Electronic Access to Health Information* specifically expect that: “The provider ensures [that] the patient’s health information is available for the patient (or the patient’s authorized representative) to access using any application of their choice that is configured to meet the technical specifications of the API in the provider’s”.

Two important activities fostering patient-centered care are: (1) **patient access** to health care information and (2) **patient involvement** in care.

Research has shown that patients believe that control of their health information: positively affected communications with their providers; enhanced knowledge of their health; improved self-care; and, allowed for greater participation in improving their quality of care. In addition, research also suggests that control of their health care records increased patient health literacy by increasing patient knowledge and Consumer Right to Direct and Control Transmission

understanding, which in turn results in improved patient satisfaction with care. Such research also suggested that this has resulted in a higher likelihood of follow up from abnormal test results and informed decision-making when seeking care.

Patients who are in control of their health care information have also been shown to visit providers less frequently and to have increased participation regarding their long-term care management. Control of records appears to empower patients and enhance contributions to care. Patients have shown improved recall and understanding of medical information, without generating substantial anxiety or concern. There has also been evidence of increased treatment adherence in some health care conditions with the strongest evidence of benefit coming from studies of obstetric patients.

Therefore, increasing the patient's ability to control their health care data is shown to have potential benefit for all parties involved in the care of a patient. The purpose of this Use Case is to set forth the policies and procedures governing the manner in which the health care Consumer may request, direct and control transmission of their own personal Data within the HSX databases through the use of the MarketStreet Platform.

2. Scope

- The Consumer Use Case pertains to all patient Data stored centrally within the HSX databases, and such patient Data that can be accessed in a federated model. This Data includes, but is not limited to, the following:
 - Allergies, Care Team, Demographics, Health History, Lab Results, Medications, Problems, Procedures, Immunizations, and Vitals
- If a Patient/Consumer previously has opted-out of HSX, that Consumer/Patient's Data will not be shared unless and until the Consumer/Patient opts-back in.
- HSX considers this a Non-Treatment Use Case.
- HSX will ensure the secure transmission of all clinical health information that is protected health information (PHI), and encryption shall be implemented and maintained throughout all HSX storage and transmission processes.
- To the extent that personal Data may include Super Protected Data (as such term is defined in HSX Policies), now or in the future, HSX will comply with all applicable state and federal requirements governing the sharing of such Data, including any requirements for specific consent or notice language, as applicable.

3. Policy

The Consumer Use Case adheres to the following guidelines, policy and legal frameworks supporting individuals' access and control to their electronic health information and personal health information:

- ONC Draft Trusted Exchange Framework (released January 5th 2018)
- Promoting Interoperability (PI), Program previously known as MU3 – Meaningful Use 3; Patient Electronic Access to Health Information (August 2017)
- MITA 3.0 – Medicaid Information Technology Architecture (March 2012)
- 21st Century Cures Act (Secretary of HHS)
- Health Insurance Portability and Accountability Act of 1996 (HIPAA)
- HIPAA Privacy and Rules
- HITECH Act of 2009
- HSX Member Policies
- HHS Guidance Document governing Patient Access rights

Consumer/Patient-related access to their personal Data for any purpose does not require HSX to utilize the Use Case Governance Policy and processes for data sharing.

In the event a misuse of Data is alleged or identified, HSX shall follow the procedure outlined in the HSX Data Misuse Policy. HSX monitors the use of Data in this Use Case in accordance with the Audit and Monitoring Policy.

HSX will establish and implement Authentication and Consent protocols, which comply with all applicable federal and state law, to ensure that the release of patient information is securely and properly transmitted to the recipient identified by the Consumer/patient.

Personal health Data transmitted through HSX MarketStreet may not reflect the complete medical history and should not be used as a substitute for official health records or any professional medical judgment. There will be a disclaimer to this effect prominently posted for Consumers/Patients to view in the applications they use to request their personal Data maintained in the HSX Network.

This Consumer Use Case supports the intention of the HSX membership to implement aspects of the *21st Century Cures Acts* requirement of permitting the access, exchange, and use of electronic information.

4. Procedures

The Consumer Use Case requires HSX, Consumers/Patients and participants of HSX MarketStreet to implement the following minimum procedures:

- The Consumer/Patient may make a request only through a “secure medium” that has been vetted through HSX’s Innovation, Research & Development Division (IRD Division) and approved by the HSX Innovation Committee (hereinafter, an “**Approved Medium**”);
- An Approved Medium may, for example, include a mobile application or a web portal that has implemented Authentication and obtains Consumer/Patient Consent that meet the minimum standards adopted by the HSX IRD Division and approved by the HSX Innovation Committee, which in no case may fall below required federal and/or state legal requirements and best practices and standards in the industry;
- In general, Authentication and Consent requirements will be based upon the existing HSX Privacy and Security framework for MarketStreet initiatives;
- All clinical items will be tagged with the original Data sources thereby identifying the provider of the Data to the Consumer/Patient; and
- Any issues (i.e., perceived errors or requested corrections) related to the content of Consumer/Patient’s personal Data must be directed back to the Data provider source.

Additional procedures or protocols may be added, at the discretion of the HSX IRD Division as needed to enhance or ensure adequate security of Data and adhere to Consumer/Patient’s expressed preferences for directing and controlling transmission of their personal Data.

5. Enforcement

The HSX Innovation, Research and Development Division is responsible for monitoring the implementation of this Use Case in accordance with HSX policies, under the direction of the President and the HSX Innovation Committee.

6. Additional References

Ammenwerth E, Lannig S, Hörbst A, Muller G, Schnell-Inderst P. Adult patient access to electronic health records (Protocol). *Cochrane Database of Systematic Reviews* 2017, Issue 6. Art. No.: CD012707. DOI: 10.1002/14651858.CD012707.

Ross, S. E., & Lin, C.-T. (2003). The Effects of Promoting Patient Access to Medical Records: A Review. *Journal of the American Medical Informatics Association : JAMIA*, 10(2), 129–138. <http://doi.org/10.1197/jamia.M1147>

Woods, S. S., Schwartz, E., Tuepker, A., Press, N. A., Nazi, K. M., Turvey, C. L., & Nichol, W. P. (2013). Patient Experiences With Full Electronic Access to Health Records and Clinical Notes Through the My HealthVet Personal Health Record Pilot: Qualitative Study. *Journal of Medical Internet Research*, 15(3), e65. <http://doi.org/10.2196/jmir.2356>

7. Definitions

- MarketStreet – a marketplace of API (application
For a complete list of definitions, refer to the *Glossary*.

Policy Owner	Innovation, Research, and Development	Contact	Brian.Wells@healthshareexchange.org
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Related Documents	Data Misuse Policy Audit and Monitoring Policy Glossary		

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