



The Office of the National Coordinator for
Health Information Technology



**U.S. Department of Health and Human Services
(HHS)
The Office of the National Coordinator for Health
Information Technology (ONC)
eConsent Trial Project
Patient Educational Material/Text for Stories**

**Produced for the U.S. Department of Health and Human Services by:
APP Design, Inc.**

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Contents

Contents ii

1.0 Main Script..... 1

2.0 Additional Information/Drill Down Script 4

3.0 Script Reviews 14

Tables

Table 1: Main Script 3

Table 2: Additional Information Script..... 14

1.0 Main Script

Below is the script that will be presented as one video to patients who select the “Consent Decision Overview” button. The separate screens below were created for design purposes and will not be denoted during the video or on the virtual menu presented to patients.

| Screen | Topic Name | Narrative |
|--------|---|---|
| 1 | What is this consent decision about? | <p>This is about your choice to allow your health care providers to access your health information through a Health Information Exchange (“HIE” for short) for medical treatment and related services.</p> <p>This is different from:</p> <ul style="list-style-type: none"> - A HIPAA notice your doctor asks you to sign, or - A consent for a medical procedure. |
| 2 | What is an HIE? | <p>An HIE is a regional network that exchanges health information from participating health care providers securely over the Internet.</p> <p>The HIE in Western New York is HEALTHeLINK.</p> |
| 3 | What information can be accessed through HEALTHeLINK? | <p>As allowed by law, the information that can be accessed through HEALTHeLINK may include your:</p> <ul style="list-style-type: none"> • Name, • Address, • Social security number, • Medication history, • Test results, • Treatment history, • Health insurance information, and • Sensitive health information like mental health, domestic violence, genetic test results, HIV test results, sexually transmitted infections, and substance use. |

Patient Educational Material/Text for eConsent Pilot Stories

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| 4 | Who can access my information through HEALTHeLINK? | <p>Your health information is available to participating provider organizations (like hospitals, doctor offices, and pharmacies) through HEALTHeLINK but you can control access by making a consent decision.</p> <p>If you give consent to allow access, select staff (like a doctor or nurse) at participating provider organizations WILL have access to your health information through HEALTHeLINK WHEN they are directly involved in your care.</p> <p>Your health information through HEALTHeLINK will not be used for these purposes:</p> <ul style="list-style-type: none"> - Employment, - Insurance sales, or - Advertising and marketing |
| 4.5a | Can I access my health information through HEALTHeLINK? | <p>You may request access to your health information from your health care provider at any time. But HEALTHeLINK does not provide direct access to you.</p> |
| 5 | How is my health information secured by HEALTHeLINK? | <p>HEALTHeLINK has put safeguards in place to secure your health information.</p> <p>HEALTHeLINK follows federal and state laws, and state and local policies, to protect your health information.</p> <p>There are penalties for persons and organizations who improperly access or use your health information through HEALTHeLINK.</p> |

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| 6 | What are my consent decision options? | <p>Yes means staff involved in your care at ALL participating provider organizations can access your health information through HEALTHeLINK.</p> <p>Yes, Except means staff involved in your care at SOME participating provider organizations can access your health information; you must list which participating provider organizations will not have access through HEALTHeLINK.</p> <p>No means NO staff involved in your care at any participating provider organization can access your health information through HEALTHeLINK.</p> <p>No, Except means NO staff involved in your care at any participating provider organization can access your health information through HEALTHeLINK EXCEPT in a medical emergency.</p> |
| 7 | Other important information | <p>If you do not provide a consent decision, the consent decision remains “No, Except.”</p> <p>You have the right to change your consent decision at any time by asking your health care provider.</p> <p>You can make your consent decision now by pressing the yellow button. Or, you can learn more about making a consent decision using the blue button.</p> |

Table 1: Main Script

2.0 Additional Information/Drill Down Script

The purpose of the additional information content is to supplement the material produced in the educational video denoted as the main script, presented above, in which patients can explore topics at their discretion. The following screens will be produced to align to seven topical areas that will be available for patients to navigate on the tablet (see Button Name column).

| Screen | Topic Name | Button Name | Narrative |
|--------|----------------------|-----------------------|--|
| 1 | More on HIEs | HIEs and HEALTHe-LINK | <p>In general, a health information exchange (HIE for short) is a private network to electronically access and share patient health information. This is done securely over the Internet so that authorized health care professionals can access and share patient health information in real-time.</p> <p>The type of health information available through an HIE depends on the HIE.</p> <p>HIEs operate within a specific geographic region — a city, county, region, state or interstate area. There are more than 250 HIEs in the United States.</p> |
| 2 | More on HEALTHe-LINK | HIEs and HEALTHe-LINK | <p>HEALTHeLINK is the HIE in Western New York which includes the metropolitan Buffalo area and the surrounding eight counties. As of today, over 2,400 participating provider organizations (also referred to as organizations or participants) participate in HEALTHeLINK.</p> <p>HEALTHeLINK is a not-for-profit organization. It is also referred to as a Regional Health Information Organization (RHIO). HEALTHeLINK provides an Internet-based service that allows participating provider organizations, for example, doctors, hospitals, laboratories, radiology facilities, pharmacies, and nursing homes, to more easily access your health information so that they can use it to care for you and to better coordinate your care.</p> <p>The goal of HEALTHeLINK is to improve the quality, safety, and efficiency of health care in the Western New York region.</p> |

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| | | | <p>A complete list of the participating provider organizations in HEALTHeLINK’s network is available at the following link: www.wnyhealthelink.com/Home/Patients/Participants</p> |
| 3 | <p>Why give access to your health information through HEALTHe-LINK?</p> | <p>Why Give Access?</p> | <p>Allowing access to your health information through HEALTHeLINK can allow your health care providers who are in a participating provider organization to work more efficiently together to treat your illness or injury, and at lower costs to you. Your information would always be available to your participating provider organizations’ providers, even if your doctor’s office was closed. This would be especially helpful if you ever needed treatment after hours or at an emergency room.</p> <p>Because your health information would be available in real-time to participating provider organizations, they would be able to coordinate your care. For example, they would be able to see your recent test results and potentially avoid ordering the same test.</p> <p>By seeing what tests other providers may have ordered for you, what procedures you may have had, and what medications you may have recently filled, your care may be better coordinated. All of your providers in the HEALTHeLINK network would have the benefit of having your health information available to them whenever it was needed to better care for you. This may result in lower costs for you as tests would not necessarily need to be repeated, saving you an additional copay.</p> <p>Regardless of your consent decision, public health officials would have the ability to access needed information for use in detecting, responding to, and preventing health threats to protect and promote the health of a community. HIEs can help public health officials with duties such as infectious disease investigation by allowing immediate access to patient information.</p> |

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| | | | <p>As you will see on HEALTHeLINK’s consent form, your electronic health information may be used for the following purposes to:</p> <ul style="list-style-type: none"> - Provide you with medical treatment and related services. By related services, we mean laboratory or diagnostic services as well as clinician consultations and referrals to a specialist. - Check whether you have health insurance and what it covers. However, at this time, HEALTHeLINK does not provide this service. - Evaluate and improve the quality of medical care provided to all patients. We mean allowing access to clinical information for care coordination, disease management, and focusing the delivery of care around the patient. |
| 4 | <p>More examples on the type of information that participating provider organizations’ providers could be able to access through HEALTHe-LINK</p> | <p>What Can Be Accessed?</p> | <p>As you just learned, participating provider organizations would be able to access your name, address, and social security number through HEALTHeLINK. They would also be able to access your phone number, birth date, and other information that might help identify you.</p> <p>Your medication history, test results, and treatment history could also be accessible through HEALTHeLINK. Depending on when a participating provider organization joined HEALTHeLINK, this information may go as far back as 2007 when HEALTHeLINK began exchanging information. In some cases, the records may reference medical procedures before 2007.</p> <p>Your medication history is a list that may include drug name, date prescription was filled, and dosage. Test results may include the result of the test taken, along with the provider name, location, and the date you had a test done. Treatment history may include the name and date of your past procedure such as an operation.</p> |

Patient Educational Material/Text for eConsent Pilot Stories

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| | | | <p>Health insurance information that may be accessible through HEALTHeLINK includes the name and address of your health insurance company and your policy number.</p> <p>Your test results and treatment histories can cover a lot of different health issues/conditions. As allowed by law, such information could include sensitive health information related to conditions such as:</p> <ul style="list-style-type: none"> - Mental health - Domestic violence - Genetic test results - HIV test results - Sexually transmitted infections - Substance use such as alcohol and drugs <p>Federal law places a number of limits on some health care providers who provide alcohol or drug treatment programs. As a result, providers will not make your drug and alcohol treatment information available through HEALTHeLINK. If you would like more details, please contact your drug and alcohol treatment provider.</p> <p>Notes that a doctor takes when you visit the doctor’s office would not be available through HEALTHeLINK. Notes that a doctor makes when you are at a hospital may be accessible through HEALTHeLINK.</p> |
| 5 | More on who would be able to access my information through HEALTHe-LINK | Who Can Access? | <p>When you make your consent decision, you are giving or denying health care provider organizations access to your health information at the organization-level (Mercy Hospital) and NOT at the person-level (Dr. Smith).</p> <p>The HEALTHeLINK network includes different types of participating provider organizations such as:</p> <ul style="list-style-type: none"> - Hospitals and hospital systems - Doctors (including individual and group practices, primary care providers, and specialists as well as midwives and nurse practitioners) - Laboratories - Radiology centers |

Patient Educational Material/Text for eConsent Pilot Stories

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| | | | <ul style="list-style-type: none">- Nursing homes- Pharmacy networks- Nurse care managers who work for certain health insurance companies (also referred to as payers) <p>A complete list of the participating provider organizations in HEALTHeLINK’s network is available at the following link: www.wnyhealthelink.com/Home/Patients/Participants</p> <p>Your decision whether to give consent affects who can access your information through HEALTHeLINK.</p> <p>You are deciding whether staff at participating provider organizations should have access to your health information through HEALTHeLINK when they are directly involved in your care.</p> <p>Select staff means a doctor, nurse, or other staff members directed by a doctor to obtain your health information.</p> <p>All participating provider organizations have an “Authorized Contact” who decides if a particular staff member needs access to your health information through HEALTHeLINK. The organization’s Authorized Contact ensures staff members have only the proper level of access needed to perform their job duties. For example, some staff may only see your consent decision while others may see all of your information, including health information (like your lab results).</p> <p>Case managers and disease management nurses who work for health insurance companies help coordinate your care. These nurses may have access to your health information to help coordinate your care. They may not access your information for denying claims or deciding if you can get health insurance.</p> |
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Patient Educational Material/Text for eConsent Pilot Stories

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| | | | <p>Regardless of your consent decision, the law provides public health authorities and select staff at HEALTHeLINK with limited access to your health information through HEALTHeLINK.</p> <p>As allowed by state and federal law, officials at the NY County and State Departments of Health, and Organ Transplant organizations, have access to your health information through HEALTHeLINK for public health duties or organ donor purposes.</p> <p>For HEALTHeLINK to work well, information that is accessed needs to be in a readable format. It is also important to make sure the right information is matched with the right patient. As allowed by federal law, select HEALTHeLINK staff may access your health information for these purposes.</p> <p>Your health information cannot be accessed through HEALTHeLINK by employers to make hiring or firing or other employment-related decisions, by insurance companies to make coverage decisions or to set rates, to sell you products or services, or to send you marketing materials.</p> |
| 6 | Your own and family member access to your health information | Who Can Access? | <p>You and your family members will not be able to access your health information directly through HEALTHeLINK because it is a secondary source of your health information. You should request access to your health information through your doctor, who is the “primary” source of your health information.</p> <p>You have a right to access your health information directly from your provider. You can learn more about how to get access to your health information by visiting this website: http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/consumer_rights.pdf</p> |
| 7 | How HEALTHe-LINK protects | Is My Information Secure? | <p>You may have some concerns about your electronic health information being accessed through the Internet. HEALTHeLINK takes</p> |

Patient Educational Material/Text for eConsent Pilot Stories

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| | <p>your information</p> | | <p>steps to protect and secure your health information.</p> <p>HEALTHeLINK:</p> <ul style="list-style-type: none"> - Follows the federal laws and regulations about who can look at, receive, and share your health information - Has agreements in place with provider organizations to ensure that they only use and share your health information according to the law - Instructs Authorized Contacts on how to limit who can access your health information to ensure proper level of access - Has training programs for staff members/participating provider organizations about how to protect your health information - Puts in place administrative, technical, and physical safeguards as required by HIPAA to protect your health information <p>Some examples of technical safeguards that HEALTHeLINK has in place to protect your health information include:</p> <ul style="list-style-type: none"> - Access to your health information requires a valid user ID and strong password to limit access to your information to authorized people, like your doctors and nurses. - Encryption of your information, which means your health information cannot be read or understood except by an authorized person who can “decrypt” it, using a “key” made available only to authorized people within a participating provider organization. - Audit logs record who accessed your information, if changes were made, and when they were made. HEALTHeLINK checks these logs often to protect you and your information. |
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Patient Educational Material/Text for eConsent Pilot Stories

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| | | | <p>If we suspect inappropriate use or disclosure of your information, HEALTHeLINK will investigate the incident and, where appropriate, report the incident. The participating provider organization will also investigate and, as necessary, contact you. If an inappropriate use is confirmed, penalties will be imposed in accordance with local policies and state and federal laws.</p> |
| 8 | <p>More about Privacy and Security Laws, Regulations, Policies</p> | <p>Is My Information Secure?</p> | <p>Federal and New York state laws and regulations as well as local policies help to protect your health information.</p> <p>For example:</p> <ul style="list-style-type: none"> - The HIPAA Privacy and Security Rules were issued under the Health Insurance Portability and Affordability Act or HIPAA for short. The HIPAA Privacy Rule provides federal protections for personal health information available through RHIOs such as HEALTHeLINK and gives patients’ rights with respect to that information. The Privacy Rule is balanced so that it permits the disclosure of personal health information needed for patient care and other important purposes and limits other disclosures. - The HIPAA Security Rule sets national standards to safeguard the confidentiality, integrity, and availability of your health information against unauthorized use or disclosure. - The HIPAA Privacy Rule also provides you with individual privacy rights, including the right of access to your health information. - To learn more about your health information privacy rights, you can visit this website: http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/index.html - The “Confidentiality of Alcohol and Drug Abuse Patient Records” regulations, 42 CFR Part 2, is a federal regulation that governs the disclosure of |

Patient Educational Material/Text for eConsent Pilot Stories

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| | | | <p>alcohol and drug abuse treatment information from federally assisted programs that provide drug and substance abuse treatment. These regulations limit the disclosure of any identifiable information from these programs unless the patient gives consent in writing or as is otherwise specifically allowed by law. For more information about this regulation, please visit this link: http://www.samhsa.gov/healthPrivacy/docs/EHR-FAQs.pdf</p> <p>Various state laws and regulations are also designed to protect and control the release of patient information. These include:</p> <ul style="list-style-type: none"> - The NY State Information Security Breach and Notification Act, which identifies processes and procedures that organizations in New York must follow if there is a breach of your electronic health information. For more information, you can visit this link: http://www.dhSES.ny.gov/ocs/breach-notification/ - The NY State Public Health Law, which describes who is considered a qualified person entitled to access a patient’s health information. It also describes the use and disclosure restrictions/requirements for/of certain patient health information that HEALTHeLINK must follow. You can learn more by visiting the following links: http://www.health.ny.gov/diseases/aids/facts/helpful_resources/confidentiality_law.htm or http://www.omh.ny.gov/omhweb/consumer_affairs/resources/docs/Understanding_HIPAA.pdf <p>Policy Guidance for New York RHIOs includes:</p> |
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Patient Educational Material/Text for eConsent Pilot Stories

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| | | | <ul style="list-style-type: none"> - Privacy and Security Policies and Procedures for RHIOs and their Participants in New York State: Developed with the NY State Department of Health, provide guidance to New York RHIOs relating to patient privacy and security issues. For more information, you can visit this link: http://nyehealth.org/wp-content/uploads/2012/07/Privacy-and-Security-Policies-for-RHIOS_v2.2.pdf <p>At the local level, HEALTHeLINK follows its set of policies and procedures that are specific to their operation. These are available for you to read on HEALTHeLINK’s website. For more information, please visit the link: http://www.wnyhealthelink.com/Patients/Policies</p> |
| 9 | What can I do if I think my information has been misused or inappropriately accessed? | Is My Information Secure? | <p>You can report suspected misuse of your health information accessed through HEALTHeLINK by calling one of the following:</p> <ul style="list-style-type: none"> - HEALTHeLINK at (716) 206-0993 extension 311 - New York State Department of Health toll-free at 1-877-690-2211 <p>Also, if you believe that your provider or HEALTHeLINK violated your health information privacy rights or committed another violation of the HIPAA Privacy or Security Rule, you may file a complaint with the U.S. Department of Health and Human Services Office for Civil Rights (OCR). For more information, you can visit this link: http://www.hhs.gov/ocr/privacy/hipaa/complaints/index.html</p> <p>Know that under HIPAA, any organization or person within that organization cannot retaliate against you for filing a complaint.</p> <p>Participating provider organizations and staff members who knowingly and willfully violate any HEALTHeLINK policies and/or state</p> |

Patient Educational Material/Text for eConsent Pilot Stories

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| | | | and/or federal laws protecting your health information can be subject to monetary and/or disciplinary punishments. |
| 10 | More about making your consent decision today | More Consent Decision Info | <p>If you make a consent decision today, your choice will be applied to all provider organizations currently participating in HEALTHeLINK.</p> <p>If a new participating provider organization joins HEALTHeLINK after you made your consent decision today, the organization will NOT have access to your health information until you update your consent decision. In the future, if you go to a participating provider organization that joined after making your initial consent decision, you may be asked to make a consent decision again.</p> <p>Your doctor will still treat you, regardless of your consent decision.</p> <p>If you have been named to care for someone else, serve as a health care representative, or help someone make their health care decisions, you can make a consent decision for that person.</p> |
| 11 | More on how to update or change your consent decision after today | Can I Change My Mind? | <p>You have the right to change your consent decision at any time by asking your health care provider, or you can contact HEALTHeLINK at 716-206-0993 extension 311.</p> <p>Your consent decision is valid until you decide to withdraw it.</p> |

Table 2: Additional Information Script

3.0 Script Reviews

All scripts were reviewed for readability. Shorter word options were substituted where feasible (e.g., “however” to “but,” “appointed” to “named”). However, to achieve consistency in language, terms such as “participating provider organizations” and “information” were used. These terms drove higher grade level results from the readability formula given length, syllable count, and sophistication of words. Furthermore, the use of legal clauses added to a higher readability level. HEALTHeLINK’s legal counsel, HEALTHeLINK’s privacy and security officer, and the physician chair of HEALTHeLINK’s Executive Steering Committee reviewed the main and additional information scripts before submitting them to HHS for review and approval.

Patient Educational Material/Text for eConsent Pilot Stories

Reviews of the main and additional information scripts were also conducted by ONC, the Office of General Counsel (OGC), and the Office for Civil Rights (OCR).