



March 13, 2015

The Honorable Sylvia Mathews Burwell
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

RE: Workgroup for Electronic Data Interchange Blue Button Initiative Survey Results

Dear Secretary Burwell:

In its advisory role under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), the Workgroup for Electronic Data Interchange (WEDI) periodically brings to the attention of the Department of Health and Human Services issues related to healthcare information exchange that it believes merit review and consideration.

In 2013, WEDI conducted its first survey on industry awareness and adoption regarding the usage of the "Blue Button" implementation guide for exporting patient healthcare records. In 2014, WEDI re-surveyed the industry to determine adoption since that time. "Blue Button" is a way for patients to get easy, secure online access to their health information.

The survey was opened October 31, 2014 with 274 providers, health plans, vendors and clearinghouses participating online before it was closed December 8, 2014.

Below are some key observations from the 2014 survey in comparison with 2013 findings:

- 1. Relying on integrated electronic health record and medical device data to populate personal health records (PHRs) increased.** While provider respondents remained relatively consistent in their use of integrated EHRs, a significant increase occurred for government respondents from 60 percent in 2013 to 100 percent in 2014. Both of these groups saw medical device data increase, with government respondents going from zero in 2013 to 25 percent in 2014. The shift for provider respondents is likely reflective of greater participation in Meaningful Use incentive programs.
- 2. Ensuring awareness of Blue Button as an industry-wide tool remains an opportunity.** The overall shift of awareness appears to have decreased, but upon further review of responses by respondent type, we found greater participation by behavioral and allied health providers in 2014. We believe the provider respondent increase of no awareness from 32 percent in 2013 to 49 percent in 2014 is impacted by the increase of more provider respondent types in 2014 that are ineligible for meaningful use incentives.
- 3. Offering the PHR to all patients when implementing a PHR continues to be significant.** Respondents are at varying stages in terms of PHR implementation, some have implemented, others are implementing this year and others are still in the planning stages. What remains constant is the high percentage (80 percent in 2014) of respondents that are offering the PHR to all patients/members as opposed to only making it available to select subsets of their patients/members.



4. **Enabling the patient/member to retain control over who has access to their PHR data through privacy controls continues to be important.** As the industry sees greater consumer engagement in their healthcare, privacy and security of patient/member data is of the utmost importance. No functionality was removed; rather there were shifts in which functionalities are more prominent. For example, health plan respondents from 2013 to 2014 showed a decrease in opt-out capability (50 to 22 percent) and an increase in opt-in capability (69 to 89 percent).
5. **Transmitting data to patients, providers or authorized third parties appears to occur through DIRECT.** Health plan and provider respondents both showed an increase in use of DIRECT for transmitting data, while government and technology developer respondents showed a decrease in use of DIRECT. All respondent groups showed a decrease in use of DIRECT with Secure Blue Button Trust with an overall decrease from 15 percent in 2013 to 8 percent in 2014.
6. **Providing patients with a better overall experience continues to show traditional communication methods as top priorities.** In 2014, the top three priorities for respondents continue to be email, text messages and direct mail. However, more organizations are recognizing the importance of providing mobile services, sending data to third party apps and services and allowing data to be downloaded in multiple formats.

Based on the survey results, industry stakeholders are slowly building awareness about the Blue Button Initiative. It appears that usage and adoption of personal health records continues to grow among industry stakeholders. WEDI offers our support to HHS to help educate the industry on the usage of the Blue Button Implementation Guide in order to improve adoption of a standardized approach to exporting personal health records.

WEDI will continue to monitor industry progress towards the implementation of the Blue Button initiative and offers our assistance to the Office of the National Coordinator (ONC) on deepening industry awareness. WEDI appreciates the opportunity to work with your office to continue outreach efforts and to identify best approaches for achieving industry awareness.

Devin Jopp, Ed. D., President and CEO of WEDI, or I would be pleased to answer further questions. You may contact Devin at djopp@wedi.org or (202) 618-8788.

Sincerely,

Jean Narcisi
Chair, WEDI

cc: Karen DeSalvo, M.D., M.P.H, Acting Assistant Secretary for Health, National Coordinator for Health Information Technology
Lisa Lewis, Acting National Coordinator for Health Information Technology
Shana Olshan, National Standards Group
WEDI Board of Directors



Survey Questions and Results

This section highlights results from the November 2014 survey and compares them to our October 2013 survey.

Please describe your organization type.

The following table illustrates the number of survey respondents by type of entity:

Organization Type	2014 Responses	2013 Responses
Government Agency or Organization	20	20
Health Plan	51	67
Health System	20	6
Hospital System	24	22
Individual Hospital	14	3
Integrated Delivery System	15	4
Technology Developer	57	36
Other	73	42
Total	274	200

For analysis purposes, the following were grouped together in the provider category: health system, hospital system, individual hospital and integrated delivery system. When feasible, the responses in the "other" type were applied to the appropriate provider, health plan or government agency/organization.

Are you familiar with the Office of the National Coordinator for Health IT (ONC) patient- directed "Blue Button" initiative? "Blue Button" is a way for patients to get easy, secure online access to their health information.

Response Options	2014 Responses	2013 Responses
Yes, I am familiar with the details of this initiative	32.5%	37.2%
I've heard of the initiative, but I'm not sure of the details	34.3%	35.7%
No, I am not familiar with this initiative at all.	33.2%	27.1%

While the results are fairly consistent from 2013 to 2014, there is a slight increase in those not familiar with the initiative at all. Examining the organization types whose response was not familiar at all, there was a greater percentage of various provider types (from 30 to 49 percent) and technology developers (from 6 to 14 percent), with other organization types remaining about the same. Many of these providers were behavioral health, allied health providers or non-hospital based facilities.



Does your organization currently offer or plan to offer a patient-directed Personal Health Record (PHR) to your members or patients?

Response Options	2014 Responses	2013 Responses
My organization is currently offering a PHR to some or all of our members.	38.9%	33.6%
My organization is currently in the process of developing or acquiring a PHR for our members, but we are unsure of when it will be released.	14.8%	8.5%
My organization plans to offer PHR access to our members sometime in 2014.	3.9%	6.1%
My organization is undecided on whether to offer PHR access to our members.	18.8%	23.8%
My organization has no plans to offer PHR access to our members.	23.6%	28.0%

The percentages from 2013 to 2014 show an overall increase in organizations that will or already are offer a PHR. The stakeholder groups whose percentages align with this are health plans and technology developers. Providers as a whole shifted to have or plan to have less PHRs and more were undecided or no plans at all. The organization type that shifted most significantly was the government agency or organization, which went from 36 percent will or already offering to only 23 percent in 2014 with the undecided or no plans to offer going from 63 to 78 percent. Given the attention within federal agencies around Blue Button, we can only surmise this shift is more related to what government agency and level, i.e. federal vs. state, the respondent was from rather than a decrease in actual intent to offer PHRs.

Please select the answer that best describes how your organization offers or plans to offer PHR access to your members or patients.

Response Options	2014 Responses	2013 Responses
All members/patients will be offered a PHR	80.5%	78.9%
A select group of members will be offered a PHR	19.5%	21.1%

The 2014 results are consistent with those from 2013, showing that the industry overall thought process is all members or patients should have access to their personal health information. This aligns with the move towards engaging consumers in their own healthcare.



Does your organization use a vendor-supplied (aka: “off-the-shelf”) product or custom developed PHR for your members or patients?

Response Options	2014 Responses	2013 Responses
My organization uses a custom developed PHR product	32.4%	32.3%
My organization uses a vendor supplied PHR product	33.3%	35.4%
My organization uses a vendor supplied PHR Product that contains customized functionality and/or features.	34.3%	32.3%

We again see little shift in the approach to how an organization will offer a PHR. When looking at these results by stakeholder group, neither health plans or providers have much shift from one approach to the other but the government agencies made a significant shift away from a vendor supplied PHR with customized functionality to a fully custom developed PHR product.

**Where does your organization get the patient data that is used to populate your PHR?
Please select all that apply.**

Response Options	2014 Responses	2013 Responses
Claims data	35.9%	44.6%
An integrated electronic health record systems (directly connected to PHR)	66.0%	53.8%
A non-integrated electronic health record system (data is input into PHR Through a non-direct connection)	12.6%	13.8%
Patient-entered data	35.0%	50.8%
Medical device data	10.7%	6.1%

The overall shift from 2013 to 2014 favors the use of electronic health record (EHR) data over claims or patient-entered data. Across the stakeholder groups, however these shifts varied. Health plans moved significantly to use of claims data and decreased use of EHR and patient-entered data while government agencies decreased claims and patient-entered data and moved to EHR data. Even though entities can be sourcing from more than one of the choices, 100 percent of government agency respondents indicated the use of data from integrated electronic EHR systems in 2014. Providers showed a decrease in use of claims data with increases in both EHR and patient-entered data. We would deduce that for providers, this reflects greater participation in Meaningful Use and associated incentive programs.



Approximately how many members/patients at your organization have accessed their PHR at least one time in the past 12 months?

Response Options	2014 Responses	2013 Responses
Less than 5%	21.5%	32.6%
5-25%	27.1%	15.2%
25-50%	7.1%	2.2%
More than 50%	1.4%	2.2%
More than 75%	4.3%	8.7%
I don't know	38.6%	39.1%

Overall the accession of the patient or member's PHR is increased by less than one percent, but the percent of patients or members that accessed their PHR rose most significantly from less than 5 percent to between 5 and 25 percent. This indicates an interest by the consumer in their health information.

Health plans, government agencies and providers alike saw the most use in the less than 5 percent or 5 to 25 percent categories. The interesting shift in this question was in the "I don't know" category, which saw a 14% decrease for the provider community and an increase for both health plans (28 percent) and government agencies (42 percent). This indicates that the provider community is doing more tracking of access to PHRs than health plans or government agencies. This again is likely a result of Meaningful Use and associated incentive programs.

Which of the following privacy controls are offered to patients with regard to their PHR?

Please select all that apply.

Response Options	2014 Responses	2013 Responses
Patient must opt-in for a PHR account to be created	78.1%	76.3%
Patient are able to opt-out of having a PHR account created for them	40.6%	44.7%
Patients can select when physicians can view records (applies to the entire record)	18.8%	23.7%
Patents can select when physicians can view certain parts of their medical record	21.9%	15.8%
Patients can request record amendments from within the PHR	31.2%	21.0%

This is another question where the shifts overall are minimal. The shifts by stakeholder group were more significant for the opt-in approach and the ability to opt-out of having one across health plans and providers, in which both saw increases in the patient opt-in requirement in order to create a PHR and a decrease in the ability to opt-out of having a PHR account. Government agencies however saw an increase in both approaches. All three stakeholder groups showed an increase in the patient's ability to control when physicians can view their records, whether the entire or by certain parts. On the technology developer side, the patient's ability to select when physicians view their records and requesting amendments of their records show as decreased for all three. These results still reflect that most PHRs are custom developed or vendor supplied with customized functionality across the three user stakeholder groups surveyed.



Which of the following data components can be viewed from within your organization's PHR?

Response Options	2014 Responses	2013 Responses
Adverse reactions	40.3%	54.8%
Allergies	66.1%	78.6%
Visit Types	51.6%	52.4%
Immunization History	64.5%	78.6%
Medications	79.0%	90.5%
Care Plan	43.6%	45.2%
Discharge Medications	40.3%	26.2%
Reason for Referral	30.6%	16.7%
Problem list	58.0%	54.8%
Procedures	59.7%	59.5%
Functional & Cognitive Status	19.4%	19.5%
Lifestyle data (e.g. smoking status)	45.2%	54.8%
Lab Values/Results	74.2%	81.0%
Family health history	53.2%	38.1%
Vital Signs (e.g. height, weight, BMI)	58.1%	52.4%
Discharge Instructions	37.1%	23.3%
Provider name and contact information	71.0%	70.0%
Claims history	38.7%	47.6%

This question shows some interesting decreases in viewable data from 2013 to 2014, including allergies, medications and smoking status. Given that availability of this data is a measure in Meaningful Use Stage 1, not making it viewable in a PHR seems to create a conflict. These decreases were consistent across health plans, providers and government organizations except government organizations did show an increase for medications. If a future survey is conducted, more information around this might collected in order to better understand the changes.

**Which of the following features and/or functionalities are supported within your organization's PHR?
Please select all that apply.**

Response Options	2014 Responses	2013 Responses
Download or print health information	87.1%	94.6%
Request health record amendments from within the PHR	45.2%	16.2%
Securely message health care providers	58.1%	51.4%
Send health information to 3 rd parties outside your organization	25.8%	21.6%

The significant change in this question was in the ability to request health record amendments from within the PHR. Both the health plans and government organizations significantly increased this capability from 2013 to 2014. This again aligns with the move toward engaging consumers in their healthcare.



Does your organization's PHR support the following file formats? Please select all formats that are supported.

Response Options	2014 Responses	2013 Responses
HL7 Consolidated Clinical Data Architecture (CCDA)	55.8%	42.9%
.EOB format	13.5%	5.7%
.PDF	78.6%	80.0%
.TXT	42.3%	40.0%

The most notable increases here are the use of HL7 CCDA files and .EOB format files. In terms of stakeholder groups, the CCDA files increased for both government organizations and providers while decreasing for health plans. Support of the .EOB format increased only for health plans, decreased for providers and remained at zero support for government organizations. Health plan support remains highest for .PDF and moderate for .TXT. Providers increase support for both .PDF and .TXT. With the increase in mobile technology use in general within the industry, this is another question that might be further explored in more detail in any future survey.

**How do you transmit data to the patient, provider, or third party (app, service, or trusted entity)?
 Select all that apply.**

Response Options	2014 Responses	2013 Responses
DIRECT	39.4%	30.2%
DIRECT with Secure Blue Button Trust	7.7%	15.1%
RESTful API	10.5%	7.6%
I don't know	54.8%	58.5%

Most respondents showed an increase in both DIRECT and RESTful API use with a decrease in DIRECT with Secure Blue Button Trust use from 2013 to 2014. Given the work being conducted in ONC's Standards & Interoperability Framework around the use of Secure Blue Button Trust, these results may be more reflective that trust bundle pilots are still ongoing and those actively engaged in using the Blue Button Trust bundles may not have been respondents in 2014.

Health plan and provider respondents both showed an increase in use of DIRECT for transmitting data, while government and technology developer respondents showed a decrease in use of DIRECT. All respondent groups showed a decrease in use of DIRECT with Secure Blue Button Trust with an overall decrease from 15 percent in 2013 to 8 percent in 2014.



Please rank the following by highest priority in providing the patient with a better overall experience (Scale of 1 to 10, 1 = highest priority, 10 = lowest priority):

Response Options	2014 Ranking	2013 Ranking
View data in a clear and meaningful way	9.3	9.1
Download the data in multiple formats	6.1	6.6
Providing additional information to help make better decisions	7.6	7.6
Sending data to third party apps and services	5.5	6.1
Sharing information with providers	7.3	7.0
Providing a mobile site or application	5.4	5.6
Mailing media or paper content directly	4.0	4.2
Text message alerts or notifications	5.1	4.7
E-mail campaigns or newsletters	3.2	3.0
Other	1.6	1.2

There were negligible changes in the priority rankings of the items and their impact on patient experience. Given the adoption rates shown earlier, i.e. the low percentage of patients or members accessing their PHRs, this is not surprising. As adoption increases and greater numbers of consumers access their PHRs, these indicators should be re-evaluated for any changes in drivers of experience.

For each section, select the fields that are important to share with the patient and list any others that are not captured here.

In 2014, respondents were first asked whether they were part of a payer organization in order to be directed to these questions. In 2013, these questions were open to all respondents. Due to this variance, the total number of respondents for each question is noted.

Payer & Coverage Information

Response Options	2014 Responses	2013 Responses
Payer Name	96.7%	96.8%
Payer ID Type	43.3%	41.3%
Payer ID Code	26.7%	28.6%
Plan ID	70.0%	52.4%
Payer web site	73.3%	73.0%
Eligibility period start date	83.3%	85.7%
Eligibility period end date (if applicable)	73.3%	77.8%
Plan Type (e.g. Medical, Pharmacy, etc.)	80.0%	85.7%
Primary Insurance vs. Secondary	60.0%	69.8%
Total Respondents	30	63



The most significant change from 2013 to 2014 is the increase in Plan ID and decrease in Plan Type. The shift was seen primarily in the provider responses with the health plan responses being opposite the overall trend. This result is understandable between the industry concerns and confusion surrounding the Unique Health Plan Identifier (HPID) along with low perceived value of HPID within standard transactions found in WEDI's Fall 2014, HPID Survey.

Patient Information

Response Options	2014 Responses	2013 Responses
Patient Name (Last, First)	100.0%	96.8%
Patient Identifier (e.g. Member ID#)	96.4%	80.6%
Total Respondents	28	62

The importance of sharing the patient information within the PHR with the patient consistently rose from 2013 to 2014. As this is of absolute importance to ensuring the information is for the right patient, these results are not surprising.

Provider Information

Response Options	2014 Responses	2013 Responses
Provider ID Code (e.g. NPI)	70.0%	53.2%
Provider Name (Last & First name or organization)	96.7%	96.8%
Provider web site	33.3%	43.6%
Total Respondents	30	62

As provider identifiers are more broadly available to patients, the increase in sharing this information so the patient again can confirm the right provider is linked to them in the PHR is evident. Sharing the provider's website information was deemed more important in 2014 only by the health plans. Providers actually reduced to zero felt it was important enough to share in the PHR, which makes sense as generally patients would access their PHR when offered by their providers through the provider's website.

Claim Level Detail

Response Options	2014 Responses	2013 Responses
Claims ID Number	86.7%	76.7%
Date of Service	96.7%	96.7%
Procedure Code Type (e.g. CPT, HCPCS, NDC Rx code, ICD-9 CM procedure)	66.7%	65.0%
Procedure Code(s)	83.3%	76.7%
Procedure Description	80.0%	88.3%
Diagnosis Codes	86.7%	73.3%
Diagnosis Descriptions	83.3%	83.3%
Total Respondents	30	60



While Claims ID number, Procedure Code(s) and Diagnosis Code(s) increased overall in 2014, providers responding indicated for all three of these that it was less important to share in the PHR. This change is understandable in the event a patient is only accessing a health plan offered PHR and not following up with their physician for questions or concerns about what they see listed for diagnosis and procedures. Claims data facilitates the aggregation of data for care coordination but does not replace the need for the patient to engage with their physician about the care they are receiving.

Health Financial Amounts

Response Options	2014 Responses	2013 Responses
Provider Charged Amount	86.2%	88.1%
Allowed/Negotiated Amount	82.8%	83.0%
Paid-to-Provider Amount	79.3%	88.1%
Patient Responsibility (Amount)	86.2%	93.2%
Deductible Amount	82.8%	91.5%
Coinsurance Amount	82.8%	89.8%
Copay Amount	82.8%	88.1%
Coordination-of-benefits (COB) Amount	62.1%	69.5%
Adjustments	69.0%	78.0%
Explanatory Codes	69.0%	79.7%
Total Respondents	29	59

In this section, all financial amounts decreased with respect to importance of sharing within the patient’s PHR. This was mirrored in the health plan responses while government organizations and providers mostly increased the importance of sharing. This shift is not interpreted as a decrease in the value of this information to the patient, rather an indicator of the appropriate way to communicate this to a patient. Providers and patients rely on remittances or explanation of benefits for this information. While in the future patients may receive their explanation of benefits as part of their PHR, communicating this information to providers through a patient’s PHR would not replace the HIPAA standard remittance transaction.

Other Health Data Elements found in non-EMR data sources

Response Options	2014 Responses	2013 Responses
Laboratory result data (e.g. LOINC-coded results)	70.0%	86.5%
Wellness & Care Management Program Alerts & Invitations	90.0%	80.8%
Security & Authentication Hashes	30.0%	44.2%
Total Respondents	20	52

The shift in importance of sharing laboratory result data aligns with the general shifts seen above around claims data. Wellness data continues to be seen as increased value across all stakeholders, which would correlate to the overall importance and awareness of health and wellness by the consumer. The decrease in importance of security and authentication hashes we do not believe indicates that security is not important; rather it reflects the shift in some environments to digital signatures for authentication purposes.



CONCLUSIONS

Based on the survey results, industry stakeholders are still building awareness about the Blue Button Initiative but that awareness seems to have diminished slightly since 2013. It appears that usage and adoption of personal health records continues to grow among industry stakeholders. WEDI offers our support to HHS to help educate the industry on the usage of the Blue Button Implementation Guide in order to improve adoption of a standardized approach to exporting personal health records.

WEDI will continue its efforts to move the industry forward and plans to continue its surveys to gauge industry awareness. WEDI appreciates the opportunity to work with HHS in this regard.