

## Comparing Patient-Reported Medical Problems with the Electronic Health Record Problem List

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### Abstract

Electronic health record (EHR) problem lists are extremely important, and yet they are often incomplete and out of date. We compared the EHR problem list to a self-reported problem list obtained via a tablet-administered questionnaire to identify potential synergy.

We conducted a retrospective review comparing the EHR problem list to the patients' self-reported problem list during the year of 2011. To confirm the accuracy of patient self-reports, we also analyzed medication lists, and laboratory results for two selected conditions, hypercholesterolemia and diabetes mellitus.

Overall, 1472 patients at the Massachusetts General Hospital (MGH) used the tablet questionnaire. Of these, 843 (57.27%) had no problem reported in the EHR and some problem reported on the tablet ("Tablet Only"); 42 patients (2.85%) had no problem reported on the tablet or in the EHR ("None"); 17 patients (1.15%) had some problem reported in the EHR and no problem reported on the tablet ("LMR Only"); and 570 patients (38.72%) had some problem reported both on the tablet and in the LMR ("Both"). Overall, we studied 59 conditions, of which twelve had enough patients to run Chi Square analysis. Of the 12 conditions analyzed, 10 were significant, and 9 out of 10 conditions favored the tablet-administered questionnaire. Medication lists and laboratory results were reviewed to confirm the presence of the selected conditions.

We reviewed the EHR problem list one year after the study was initiated to update the conditions under study. The additional data corroborated 107 additional self-reported conditions in 97 patients.

In summary, a self-administered tablet questionnaire is an acceptable method for collecting the medical history. When combined with the EHR problem list, self-reported medical history is optimal for obtaining the most accurate problem list possible.

**Keywords:** Electronic health record; Problem list; Patient engagement; Data quality

### Introduction

Many had hoped that the implementation of the electronic health record (EHR) would improve quality of care and enhance safety by making data for secondary purposes more accessible to healthcare providers [1]. However, the preponderance of free text, coupled with the high likelihood of redundant, contradictory, incomplete, or missing data, has been a barrier to achieving this goal. In particular, the EHR problem list suffers from being both incomplete and unstructured [2]. The issue is that creating and maintaining a comprehensive and accurate problem list is critical and yet difficult to execute.

Patients can be engaged to assist in this activity by completing self-administered questionnaires. While paper-based questionnaires have been the norm, these tools require transcription of that information into the EHR, costing time or preventing data entry. An alternative is to use patient-entered questionnaires, delivered via the Web or on a PC tablet, to electronically collect structured data, thereby eliminating the need for data entry by the professional staff.

Armed with the knowledge that problem lists are often incomplete, [3] we studied the degree of missing data in the problem list in the EHR (Longitudinal Medical Record, or LMR) at MGH, and examined the accuracy of a self-reported problem list from a tablet questionnaire (hereafter referred to as the Tablet). Our goal was to compare the accuracy and completeness of patient-entered versus the EHR problem list.

### Materials and Methods

#### General methods

With Massachusetts General Hospital - Partners, Boston MA

Institutional Review Board approval and in compliance with all appropriate regulations, we conducted a retrospective chart and database review. Patients seen at the Avon Breast Evaluation Center and a pilot sample of those seen at the Pre-Anesthesia Testing Area (PATA) completed a Tablet questionnaire via the Hughes RiskApps, LLC software [4,5]. Patients were asked to fill out questions regarding their medical history, family history and risk factors. A retrospective analysis was carried out on patients seen between January 1, 2011 and December 31, 2011, comparing the problem list available in the EHR (and other corroborating data from the EHR) to the patients' self-reported problem list generated using the Tablet questionnaire. The data was not anonymized and de-identified prior to analysis due to need to join multiple patient records.

#### Methods regarding accuracy of patient-entered data compared to EHR problem list

To produce consistent comparisons between the EHR and the Tablet problem lists, a specific and generic SNOMED-CT (Systematized

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Nomenclature of Medicine - Clinical Terms) code was manually identified for all problems whether free text or structured data. The code described the specific problem listed in the EHR (usually free text) or the Tablet questionnaire. The generic code was derived in accordance with the SNOMED-CT hierarchy to identify a problem type as opposed to a specific problem, since the patient's reports are generally more generic than the physician's problem list. For example, if the patient selected "Disorder of liver" in the Tablet and the EHR had the diagnosis of "Cirrhosis of liver," the generic SNOMED-CT code would help determine whether they were likely to be describing the same disorder, but with a different level of complexity (Table 1).

The analysis was limited to problems included in the Tablet to minimize reporting bias. Table 2 contains the list of problems included in the tablet questionnaire.

Specific SNOMED CT code	Specific text	Generic SNOMED CT code	Generic text
166603001	Liver function tests abnormal	235856003	Disorder of liver
3738000	Viral hepatitis	235856003	Disorder of liver
50711007	Viral hepatitis C	235856003	Disorder of liver
40468003	Viral hepatitis, type A	235856003	Disorder of liver
442191002	Steatohepatitis	235856003	Disorder of liver
154350000	Other hepatitis	235856003	Disorder of liver
197321007	Steatosis of liver	235856003	Disorder of liver
66071002	Type B viral hepatitis	235856003	Disorder of liver
19943007	Cirrhosis of liver	235856003	Disorder of liver

Table 1: Using specific and generic SNOMED CT codes.

Studied Problems
Anemia
Asthma
Bleeding
Cardiac revascularization with bypass anastomosis
Cerebrovascular accident
Chronic obstructive lung disease
Cirrhosis of liver
Conduction disorder of the heart
Congenital heart disease
Coronary angioplasty
Diabetes mellitus
Epilepsy
Esophageal varices
Factor V Leiden mutation
Gastroesophageal reflux disease
Heart murmur
Hodgkin's disease
Hypercholesterolemia
Hypertensive disorder, systemic arterial
Hyperthyroidism
Hypothyroidism
Implantation of heart valve
Intraductal carcinoma in situ of breast
Leukemia
Malignant hyperthermia
Malignant melanoma
Malignant neoplasm of liver
Malignant neoplasm of uterus
Malignant tumor of breast
Malignant tumor of cervix
Malignant tumor of kidney

Malignant tumor of large intestine
Malignant tumor of lung
Malignant tumor of ovary
Malignant tumor of pancreas
Malignant tumor of prostate
Malignant tumor of stomach
Malignant tumor of thyroid gland
Myocardial infarction
Neoplasm of brain
Non-Hodgkin lymphoma - category
Obese
Obstructive sleep apnea syndrome
Osteoarthritis
Other hepatitis
Placement of stent in coronary artery
Pulmonary thromboembolism
Rheumatoid arthritis
Right heart failure
Sarcoma
Sleep apnea
Smoker
Steatosis of liver
Thromboembolic disorder
Thrombosis of blood vessel
Transient ischemic attack
Type B viral hepatitis
Viral hepatitis C
Von Willebrand disorder

Table 2: All studied problems.

## Methods regarding completeness

The EHR problem list was revisited in December 2012 to determine if more data had been entered for the same cohort of patients during the intervening months that might improve the accuracy of the EHR problem list and/or corroborate the patient-entered data.

## Accuracy compared to laboratory results and compared to medications list

To confirm the accuracy of patient-reported and EHR-recorded problem lists, relevant medications and laboratory results were examined for hypercholesterolemia and diabetes mellitus. For the purposes of this research, the assumption was made that the degree of corroboration determined for the selected conditions could be extrapolated to other conditions.

## Statistical methods

To make judgments about the accuracy of the sample to see if it reflected the characteristics of the patient population from which it was drawn, we ran a Chi Square test, using the contingency tables found at Vassar Stats website, <http://www.vassarstats.net/tab2x2.html> accessed on August 1, 2013.

This analysis determined whether the observed values for the tablet questionnaire and the EHR data cells deviated significantly from the corresponding expected values for those cells. A large discrepancy between the observed and expected values would generate a large  $\chi^2$  statistic, suggesting a significant difference between observed and expected values. Along with this statistic, an alpha level of significance was determined a priori and set at 0.05 and the phi coefficient was computed. Values of  $p < 0.05$  were considered significant.

## Results

### General results

The study population, with a final sample size of  $N=1472$ , is defined as those patients who answered the Tablet questionnaire. Of this sample, 828 (56.25%) were female and 644 (43.75%) male.

### Results regarding accuracy of patient-entered data compared to EHR problem list

Of the total sample, 843 patients (57.27%) had no problem reported in the EHR with some problem reported on the Tablet (“Tablet Only”); 42 patients (2.85%) had no problem reported on the Tablet or in the EHR (“None”); 17 patients (1.15%) had some problem reported in the EHR and no problem reported on the Tablet (“EHR Only”); and 570 patients (38.72%) had some problem reported both on the Tablet and in the EHR (“Both”).

We then studied in more detail patients that had some problem reported in the EHR (“EHR Only” and “Both” - 587 patients). Among them, 70 patients (12.28%) had a perfect problem list match, which means that all problems present in the EHR problem list were present on the Tablet and vice-versa; 34 patients (5.96%) had no match (33 patients had two completely different problem lists and one patient had all problems missed by the EHR); and 466 patients (81.75%) had some problems that matched and some that were missing from one of the sources. In the last group, for the problems that didn’t match, 159 patients (34.12%) had some problems that were missed by the EHR,

and different problems that were missed by the Tablet (both lost); 252 patients (54.08%) had problems that were missed only by the EHR (pure EHR loss); and 55 patients (11.80%) had problems that were missed only by the Tablet (pure tablet loss) (Figure 1).

In this group of patients we have also compared both problems lists by disease (Figure 2).

Overall, we studied fifty-nine conditions (Tables 2 and 3), of which twelve had enough patients to run Chi Square analysis. Of the 12 analyzed conditions, 10 were significant, with a p value of  $<0.05$  (Table 4). Of those with significant differences, 9 out of 10 conditions favored the Tablet questionnaire. The only condition with significant difference between the groups that favored the EHR was hypothyroidism. For this condition, the Tablet found 68 patients and the EHR found 74.

### Results regarding completeness

After one year, we reviewed the EHR problem lists for the same cohort of patients to evaluate interval data for the conditions under study. Of the added 272 problems, 107 corroborated that which had not been previously corroborated in 97 patients (Figure 3 and Table 5).

### Accuracy compared to laboratory results and compared to medications list

As previously mentioned, medication lists and laboratory results were reviewed to confirm the presence of hypercholesterolemia and diabetes mellitus.

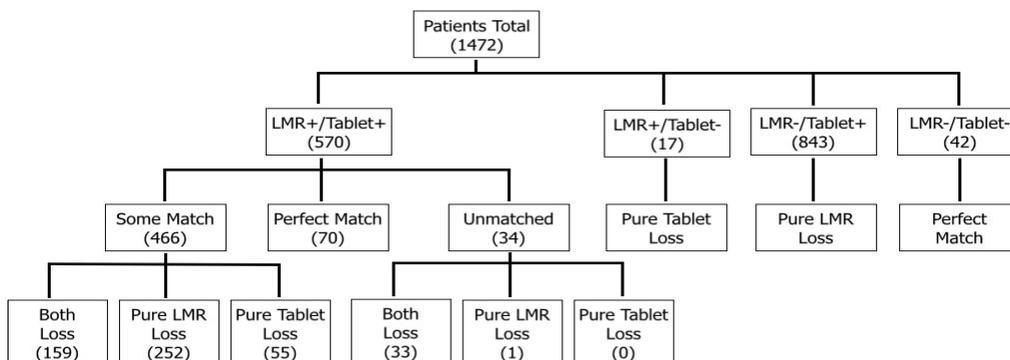


Figure 1: Results regarding accuracy of patient-entered data compared to EHR problem list.

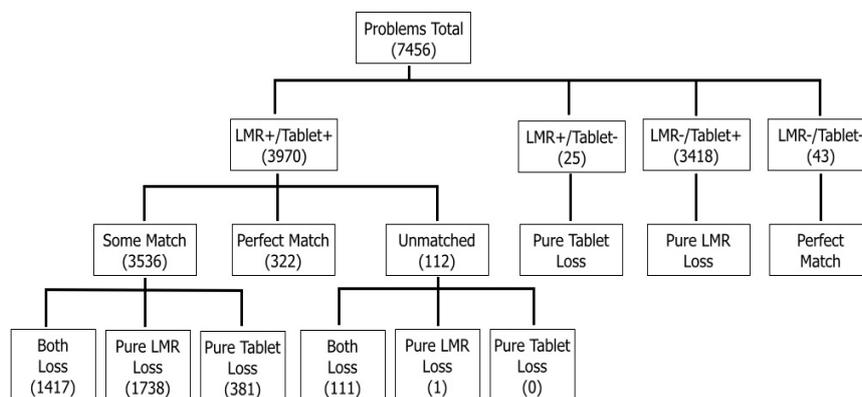


Figure 2: Results regarding accuracy of patient-entered data compared to EHR problem list by diseases.

SNOMED CT code	Text	Tablet Only	EHR Only	Tablet And EHR (Both)	Total Patients With Disease
271737000	Anemia	83	13	24	120
195967001	Asthma	41	15	51	107
131148009	Bleeding	26	1	0	27
90205004	Cardiac revascularization with bypass anastomosis	3	0	20	23
230690007	Cerebrovascular accident	6	0	10	16
13645005	Chronic obstructive lung disease	11	9	14	34
19943007	Cirrhosis of liver	2	0	3	5
44808001	Conduction disorder of the heart	40	1	41	82
13213009	Congenital heart disease	3	0	6	9
41339005	Coronary angioplasty	5	0	24	29
73211009	Diabetes mellitus	4	18	79	101
84757009	Epilepsy	4	0	11	15
28670008	Esophageal varices	5	0	0	5
307091009	Factor V Leiden mutation	3	0	7	10
235595009	Gastroesophageal reflux disease	81	64	50	195
88610006	Heart murmur	41	4	32	77
118599009	Hodgkin's disease	0	0	3	3
13644009	Hypercholesterolemia	78	48	166	292
38341003	Hypertensive disorder, systemic arterial	49	23	246	318
34486009	Hyperthyroidism	10	1	21	32
40930008	Hypothyroidism	5	11	63	79
112815000	Implantation of heart valve	3	0	4	7
109889007	Intraductal carcinoma in situ of breast	1	0	5	6
93143009	Leukemia, disease	2	0	2	4
405501007	Malignant hyperthermia	1	0	0	1
372244006	Malignant melanoma	3	2	19	24
93870000	Malignant neoplasm of liver	1	1	4	6
371973000	Malignant neoplasm of uterus	2	2	4	8
254837009	Malignant tumor of breast	13	8	65	86
363354003	Malignant tumor of cervix	2	2	2	6
363518003	Malignant tumor of kidney	9	0	7	16
363510005	Malignant tumor of large intestine	6	2	14	22
363358000	Malignant tumor of lung	7	0	7	14
363443007	Malignant tumor of ovary	2	0	1	3
363418001	Malignant tumor of pancreas	2	1	5	8
399068003	Malignant tumor of prostate	11	2	13	26
363349007	Malignant tumor of stomach	2	0	0	2
363478007	Malignant tumor of thyroid gland	3	4	10	17
22298006	Myocardial infarction	4	1	33	38
126952004	Neoplasm of brain	2	7	6	15
128929007	Non-Hodgkin lymphoma - category	2	0	5	7
414915002	Obese	138	6	73	217
78275009	Obstructive sleep apnea syndrome	1	0	3	4
396275006	Osteoarthritis	77	26	43	146
154350000	Other hepatitis	11	0	2	13
36969009	Placement of stent in coronary artery	3	0	32	35
233935004	Pulmonary thromboembolism	6	1	7	14
69896004	Rheumatoid arthritis	12	1	12	25
128404006	Right heart failure	6	0	12	18
424413001	Sarcoma	3	0	5	8
73430006	Sleep apnea	38	1	45	84
77176002	Smoker	40	18	23	81
197321007	Steatosis of liver	19	3	12	34
371039008	Thromboembolic disorder	1	0	0	1
439129009	Thrombosis of blood vessel	8	5	12	25
266257000	Transient ischemic attack	4	0	7	11
66071002	Type B viral hepatitis	6	0	1	7
50711007	Viral hepatitis C	6	0	8	14
128105004	Von Willebrand disorder	0	0	1	1

Table 3: All studied conditions by category (EHR only, Tablet only or Both).

Disorder	Tablet Only	EHR Only	Tablet And EHR (Both)	Total Patients With Disease	Neither	p-value
Anemia	83	13	24	120	467	0.001
Asthma	41	15	51	107	480	0.001
Gastroesophageal reflux disease	81	64	50	195	392	0.001
Hypercholesterolemia	78	48	166	292	295	0.0001
Hypertensive disorder, systemic arterial	49	23	246	318	269	0.0001
Hypothyroidism	5	11	63	79	508	0.0001
Malignant tumor of breast	13	8	65	86	501	0.0001
Obese	138	6	73	217	370	0.0001
Osteoarthritis	77	26	43	146	441	0.0001
Thrombosis of blood vessel	8	5	12	25	562	0.004
Chronic obstructive lung disease	11	9	14	34	553	not ss
Smoker	40	18	23	81	506	not ss

Table 4: Results of a Chi-Square analysis for the 12 conditions where statistic numbers allowed us.

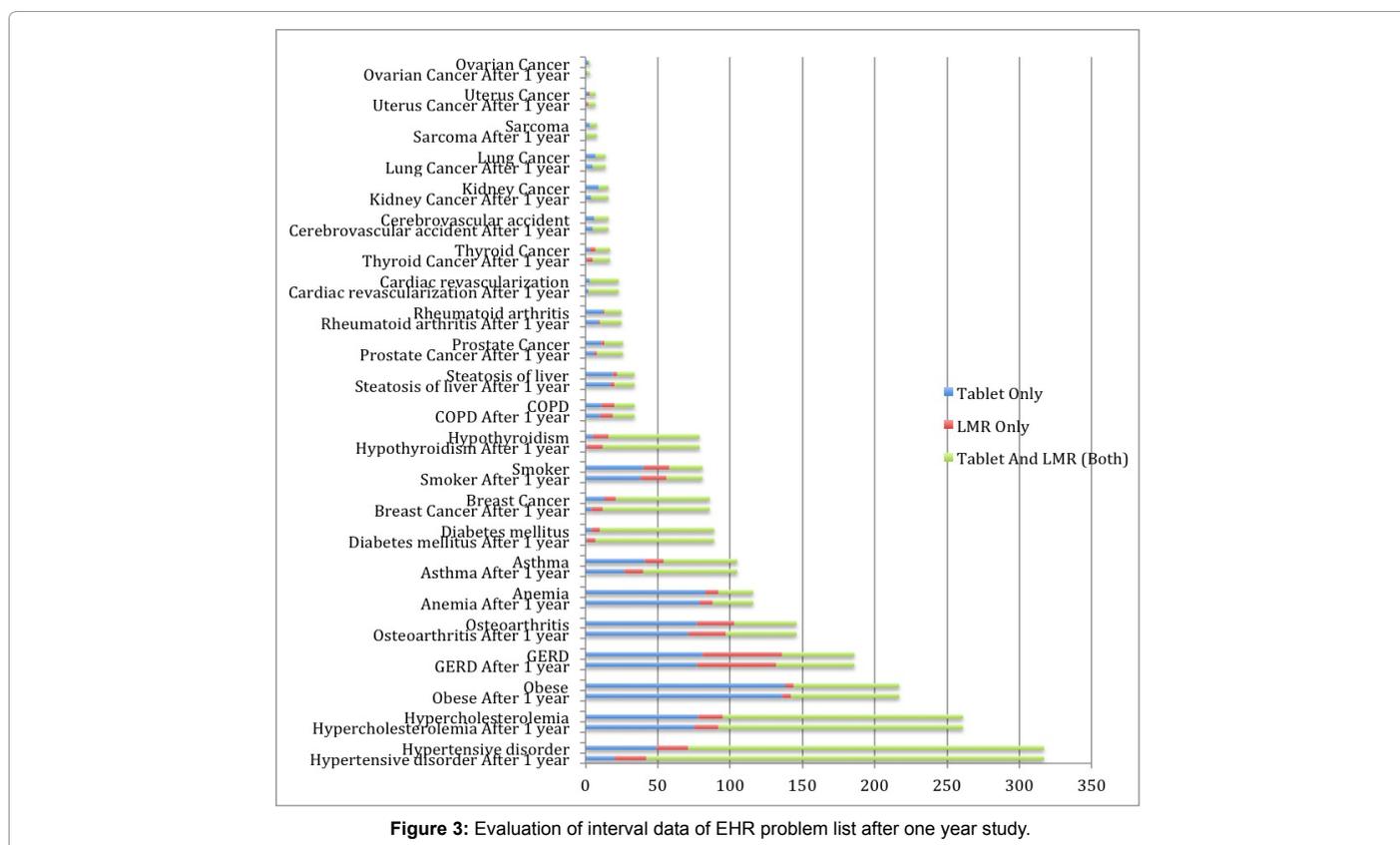


Figure 3: Evaluation of interval data of EHR problem list after one year study.

### Results for selected conditions

**Hypercholesterolemia:** We reviewed patients with hypercholesterolemia reported as a condition by the “Tablet Only” or by “EHR Only” or “Both.” Of these, 48 had hypercholesterolemia in the “EHR Only;” 78 had hypercholesterolemia reported in the “Tablet Only;” and 166 had hypercholesterolemia reported in “Both.” We established any cholesterol result >200 mg/dl as abnormal before reviewing the cholesterol laboratory tests [6]. We concomitantly reviewed patient medication lists searching for cholesterol-lowering agents (Table 6). Of the 244 patients who self-reported hypercholesterolemia, either by “Tablet only” or “Both,” 213 were corroborated by laboratory values or lipid-lowering medications (Table 7).

Of the 244 patients with hypercholesterolemia reported in the Tablet, 213 corroborated (87.29%) with the lab review, and of the 210

with hypercholesterolemia reported in the EHR, 189 corroborated (90%) with the lab review, suggesting that self-reports collected by the Tablet are as accurate as the EHR data. 26.71% of patients had hypercholesterolemia reported only on the tablet (“Tablet only”), and 16.44% of patients had hypercholesterolemia reported in the EHR but not in the Tablet (“EHR Only”).

**Diabetes mellitus:** A similar validation process was conducted with diabetes mellitus patients. Of this patient subset, 4 reported diabetes mellitus (DM) on the Tablet but the problem did not show in the EHR (“Tablet Only”) problem list; 17 had DM in the “EHR Only;” and 79 had DM reported in “Both” (Table 8). Blood glucose levels >126 mg/dl and glycohemoglobin (HbA1c) > 6.4 were considered abnormal when examining laboratory tests [7]. Of the patients taking glucose-lowering medications (Table 9): Two out of 4 patients (50%) had reported DM on the “Tablet Only;” 9 out of 17 (52.94%) had a diagnosis of DM present

SNOMED CT Code	SNOMED CT Text	Tablet Only 1 Year Follow-Up	EHR Only 1 Year Follow-Up	Tablet And EHR (Both) 1 Year Follow-Up	Number Changed*
38341003	Hypertensive disorder, systemic arterial	20	22	275	29
195967001	Asthma	27	13	65	14
254837009	Malignant tumor of breast	4	8	74	9
396275006	Osteoarthritis	71	26	49	6
363518003	Malignant tumor of kidney	4	0	12	5
399068003	Malignant tumor of prostate	6	2	18	5
40930008	Hypothyroidism	1	11	67	4
235595009	Gastroesophageal reflux disease	77	55	54	4
271737000	Anemia	79	9	28	4
13644009	Hypercholesterolemia	75	17	169	3
69896004	Rheumatoid arthritis	9	1	15	3
73211009	Diabetes mellitus	1	6	82	3
424413001	Sarcoma	0	0	8	3
77176002	Smoker	38	18	25	2
197321007	Steatosis of liver	17	3	14	2
363358000	Malignant tumor of lung	5	0	9	2
363478007	Malignant tumor of thyroid gland	1	4	12	2
414915002	Obese	136	6	75	2
13645005	Chronic obstructive lung disease	10	9	15	1
90205004	Cardiac revascularization with bypass anastomosis	2	0	21	1
230690007	Cerebrovascular accident	5	0	11	1
363443007	Malignant tumor of ovary	1	0	2	1
371973000	Malignant neoplasm of uterus	1	1	5	1

\*Number that went from "Tablet Only" to "Both" at one year

**Table 5:** Conditions that changed after 1 year in all cases the number of "Tablet Only" decreases and the number of "Both" increases.

Cholesterol-Lowering Agents
Atorvastatin
Colesevelam
Colestipol
Ezetimibe
Fenofibrate
Fluvastatin
Gemfibrozil
Lovastatin
Pitavastatin
Pravastatin
Rosuvastatin
Simvastatin

**Table 6:** Cholesterol-lowering agents.

Description	Tablet Only	EHR Only	Both	Total
Hypercholesterolemia reported	78	48	166	292
Have lab result in EHR	63	41	139	243
Lab results abnormal (>200)	19	21	51	91
Medication Present	51	22	136	209
Number of patients with some lab abnormal, or using meds, or both* same patient can be in more than one group.	61	37	152	250

**Table 7:** Hypercholesterolemia summary.

only in the EHR ("EHR Only"), and 71 out of 79 patients (89.87%) had DM reported in "Both" (Table 8). Of the 83 patients with DM reported in the Tablet, 73 corroborated (87.95%) with our lab review, and of the 96 with DM reported by EHR, 80 corroborated (83.33%) with the lab review, suggesting that self-reports collected by the Tablet are as accurate as the EHR. 4% of patients had DM reported only on the tablet

Description	Tablet Only	EHR Only	Both	Total
Diabetes reported	4	17	79	100
Have some lab result	4	16	72	92
Lab results abnormal	2	8	47	57
Medication Present	2	3	70	75
Number of patients with some lab abnormal, or using meds, or both* same patient can be in more than one group	2	9	71	82

**Table 8:** Diabetes mellitus summary.

Glucose-Lowering Agents
Glimepiride
Glipizide
Glyburide
Insulin Aspart
Insulin Detemir
Insulin Glargine
Insulin Glulisine
Insulin Lispro
Insulin NPH
Insulin Regular
Metformin
Pioglitazone
Pramlintide
Sitagliptin

**Table 9:** Glucose-lowering agent medications.

("Tablet Only") and 17% of patients had DM reported (in the EHR but not in the Tablet ("EHR Only").

It is assumed that this level of corroboration of results can be extrapolated to other conditions.

## Discussion

We have shown that the EHR problem lists in this study were incomplete, both at the start of the study and after one year of added emphasis under the Federal Meaningful Use program [8]. We found that out of 1472 patients, 57% of EHR records (843 patients) had no reported problems initially despite the presence of patient-reported problems via the Tablet. Our analysis also included a review of the EHR problem list for the same cohort of patients after one year to determine if the accuracy of the reported problems had improved. Even one year later, 49% of EHR records (716 patients) had no diseases reported in the problem list. While it might be true that a portion of patients seen at the hospital do not have a disease diagnosis, that is not true for the majority of the cases. Despite hospital support for accurate problem lists, emphasized by the problem lists being included in the Meaningful Use objective, change was minimal and the EHR problem list remained incomplete.

Statistical analysis was conducted by performing Chi-squared test to determine if there was a statically significant difference between the problems reported on the EHR compared to the Tablet. Results of the analysis, in which 10 out of 12 reported disorders were statistically significant ( $p < 0.05$ ), indicate the existence of a real difference between the lists. Among those, only one condition was reported more often only in the EHR than by patients on the Tablet. This finding would indicate that the Tablet problem list was considerably more comprehensive than the EHR problem list. The absence of problems in the problem list can be explained in part by MGH's role as a tertiary referral center. Patients are often followed elsewhere for basic care while seeking specialized care at MGH. Thus, many patients have only been seen by specialists, who may not have a vested interest in adding unrelated problems to the problem list.

We have shown that self-reported data appear to be accurate. Physician-reported diagnoses in the EHR problem list, laboratory results, and patient medication lists for hypercholesterolemia and diabetes mellitus were reviewed to validate the Tablet problem list. We have shown and it has been demonstrated elsewhere that this is a valid approach to identifying patient problems [9].

Of the 244 patients self-reported with hypercholesterolemia, 213 were corroborated by EHR, laboratory values or medication lists, supporting the accuracy of this self-reported problem. Absence of self-reporting was shown to miss 26.71% of patients with hypercholesterolemia, and absence of the EHR was shown to miss 16.44% of this patient population.

In 2002, Natarajan et al. [6] analyzed self-reports of hypercholesterolemia. They concluded that such information should be used carefully, since despite high specificity, the sensitivity was low. In our study, 87.3% of patients that reported having diagnosis of hypercholesterolemia had abnormal laboratory cholesterol levels or were taking cholesterol-lowering agents demonstrating that self-reports of hypercholesterolemia were accurate.

Of the 83 patients self-reported with diabetes mellitus, 73 corroborated with other data, supporting the accuracy of this self-reported problem list. Absence of self-reporting misses 4% of patients with diabetes mellitus and absence of EHR misses 17% of such patients.

A study conducted by Goldman et al. [10] revealed that self-reports of diabetes are an accurate estimate of the prevalence of diabetes in the studied population. Similar results were found by Goto et al. [11] in 2013, who found 70.4% sensitivity and 97.3% specificity in identifying

patients with diabetes using self-reports. In our study, 87.9% of patients with self-reported diabetes mellitus had either abnormal laboratory results (blood glucose levels and HbA1c) or were taking glucose-lowering agents, which corroborates with diabetes mellitus diagnosis.

Using both the patient-reported data and the EHR problem list is the best way of obtaining the most accurate and complete patient problem list. A study conducted in 2008 by Zakim and colleagues reached the same conclusion when comparing physician interview with computer-acquired medical histories [12]. A logical approach to this problem would be to have the patient complete a self-administered questionnaire which is then reviewed by the physician for validation. Once validated, uploading the structured data into the EHR problem list is appropriate and should be relatively simple with good EHR design.

## Conclusion

This study finds that the EHR problem list is often incomplete, [3] that the use of a self-administered Tablet questionnaire is an acceptable method for collecting family and personal history [6,10-13]. Using the EHR problem list and self-administered Tablet questionnaire together is the optimal approach to obtaining the most accurate patient problem list possible.

### Conflict of Interest Disclosures

Dr. Hughes and Dr. Drohan are co-founders of Hughes RiskApps, LLC. Dr. Hughes is a speaker at Myriad Genetics.

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### Role of the Sponsor

The funding agreements ensure the authors' independence in designing the study, interpreting the data, writing, and publishing the report.

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