**Title:** Improving Headache Diagnosis and Treatment through the Electronic Health Record (EHR), and Creating a Single-Site Model for a National Pediatric Headache Registry

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**Abstract:** Primary headache disorders in children are underdiagnosed and undertreated, contributing to the tremendous disability and high rates of school absence suffered by migraineurs.  Electronic Health Records (EHR) can be used as a tool to remedy this problem.  *The goal of this project is to develop mechanisms to improve headache diagnosis and collection of patient-reported outcome measures which will be used to track the effects of future interventions.  This will be accomplished through novel patient- and provider- data entry systems, point-of-care decision support, and creation of a Pediatric Headache Registry.*  This work will be conducted in Neurology at the Children's Hospital of Philadelphia (CHOP), and strategies for employing similar techniques in Primary Care will be explored.  The EHR-based system will be piloted at one other site, and the web-based REDCap system will be shared with the American Headache Society (AHS) and its Pediatric-Adolescent Section as a platform for a future National Pediatric Headache Registry.  Children and adolescents with headache will benefit from this project.  In 2010-2011, there were 2,967 patients in Neurology and 4,869 patients in Primary Care seen for a headache-related diagnosis.  The primary metric to measure effectiveness of the project will be the rate of diagnosis of Migraine in new patients in Neurology.  In 2012, 53.1% of new headache patients were diagnosed with migraine.  Ongoing interventions have already improved this to 56.24%.  The goal of this project will be to build on that work and increase the portion of new headache patients diagnosed with Migraine by an additional 5%.

*Note: To incorporate feedback from multiple clinicians and researchers, especially those connected with CHOP Primary Care, the project has been refined since the LOI was submitted*

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1. **Overall Goals & Objectives**

The correct diagnosis of primary headaches remains problematic.  Short patient visit times and lengthy required documentation prevent clinicians from taking the detailed history needed to make an accurate diagnosis.  Under-recognition of migraine contributes to the heavy burden of disability, whereas recognition and treatment of episodic migraine may prevent transformation to chronic headache[1]. Furthermore, even though headaches are very common in children, there is little evidence on which to base treatment decisions.

The widespread use of Electronic Health Records (EHRs) presents an opportunity to overcome these obstacles.  The EHR enables systematic data collection from patients and providers, use of clinical decision support tools, and creation of a multi-site patient registry.  Interactive computerized interviews completed by patients have been shown to produce more information than a typical history, while protecting the provider's time to focus on the patient rather than the documentation[2].  Use of clinical decision support tools to interpret this information has been proven to improve rates of diagnosis, evaluation, and prescription of therapies[3].  Finally, combining this information into a registry enables observational and pseudo-randomized trials and provides generalizable information on actual practice[4].

*The goal of this project is to develop efficient mechanisms to improve headache diagnosis and collection of patient-reported outcome measures.  This will be accomplished through novel data entry systems, point-of-care decision support, and creation of a Pediatric Headache Registry.*  The key objectives of this proposal are:

1. **To create novel patient- and provider- data entry systems to focus and standardize the information collected when evaluating and following patients with headache.**
2. **To synthesize the available evidence and the diagnostic criteria from the International Classification of Headache Disorders into point-of-care Clinical Decision Support tools to guide diagnosis and management of headache.**
3. **To develop a Pediatric Headache Registry via the EHR at CHOP as a platform for a future National Pediatric Headache Registry.**

This work will be developed in Outpatient Neurology, and then strategies for employing similar techniques in Primary Care will be explored.  These systems will be developed at the Children's Hospital of Philadelphia (CHOP) in collaboration with the American Headache Society (AHS) and its Pediatric-Adolescent Section as a platform for a future National Pediatric Headache Registry.  The data entry and decision support tools will be developed in REDCap, which is a web-based survey application for electronic collection and management of research data, then converted into the EHR to maximize utility within the clinician's usual flow.  The EHR at CHOP, EPICCare is the most common EHR vendor among hospitals with 200+ beds, so the system will be translatable to many institutions across the country[5].  The REDCap system will be fully developed and maintained for use by institutions and clinicians who do not use EPICCare.  This project reflects the focus of the RFP to develop a comprehensive learning and change strategy that facilitates improving a clinician's understanding of the appropriate diagnosis and management of migraines in the pediatric and adolescent patient, and aligns with CHOP's commitment to improve the health of children within its network and beyond.

**2. Technical Approach**

**a. Current Assessment of Need in the target area:**

The Institute of Medicine Report *Relieving Pain in America* explained the need for the type of system proposed here which maximizes the use of clinical data for the individual, and incorporates that information into a format which can be used for quality improvement and research to improve care for the population:

> "There is a need for greater development and use of such patient outcome registries that can support point-of-care treatment decision making, as well as for aggregation of large numbers of patients to enable assessment of the safety and effectiveness of therapies. These registries could help create "learning systems" that would provide clinicians with information about treatment success or failure on an ongoing basis, along with probability "filters" for information that might be particularly useful in the care of an individual patient." [6]

Past work at CHOP has highlighted several needs:

Problem #1 - Inaccurate diagnosis: Too many patients are given the non-specific diagnosis "Headache." As noted above, under-recognition of migraine contributes to continuation of the heavy burden of disability, whereas recognition and treatment of episodic migraine may prevent transformation to chronic headache[1].

*Example:* Examination of diagnostic codes extracted from the EHR EPICCare at CHOP in 2010-2011 showed that 23% of visits for headache in Primary Care received the diagnosis of Migraine and 76% were given the diagnosis, "Headache 784.0," similar to published data[7].  In Neurology, 51.9% were diagnosed as Migraine, and 41.4% were associated with the code for Headache.  Similar portions were obtained when diagnoses were examined in 2012 & 2013.

Table 1: Headache-Related ICD-9 Codes

| ICD-9 Code | Headache Type | Headache Group for Analysis |
|---|---|---|
| 307.81 | Tension Headache | Tension-Type |
| 339.0 | Cluster Headache & Other Trigeminal Autonomic Cephalgias | Other |
| 339.1 | Tension-Type Headache | Tension-Type |
| 339.2 | Post-traumatic Headache | Other |
| 339.3 | Drug Induced Headache | Other |
| 339.41 | Hemicrania Continua | Other |
| 339.42 | New Daily Persistent Headache | Other |
| 339.43 | Primary Thunderclap Headache | Other |
| 339.44 | Other complicated headache syndrome | Other |
| 339.8 | Other specified headache syndrome | Other |
| 346 | Migraine (includes Migraine without and with Aura, Chronic) | Migraine |
| 784.0 | Headache | Non-specific Headache |

The high portion diagnosed with "Headache" conflicts with the best available evidence from case series, most of which demonstrated that two-thirds of children evaluated for headache in Neurology have a primary headache disorder.

Table 2: Studies describing diagnoses in clinic-based pediatric headache cohorts:

| Author | Cohort | % Migraine | % Tension-Type |
|---|---|---|---|
| Nevo[8] | Children evaluated in Neurology Clinic for headaches for ≥3 month | 54% | 22% |
| Wöber-Bingol[9] | Children evaluated in Headache Clinic in Austria | 60% (IHS criteria for migraine or migrainous) | 36% |
| deGrauw[10] | Children evaluated at Cincinnati Children's Headache Center | 47% migraine + 35% headache with migraine component | Not specified |
| Maytal[11] | Children evaluated for headache at Montefiore Headache Unit | 52.7% migraine without aura | Not specified |
| Cano[12] | Children evaluated in Neurology Clinic | 49% met IHS criteria, 69% when all migrainous headaches were included | Not specified |

*Barriers*: The most recent Practice Parameter to guide diagnosis and evaluation of pediatric headache focused only on recurrent headaches and was published 12 years ago[13].  While the International Classification of Headache Disorders (ICHD) includes updated diagnostic criteria for primary headache disorders, the original criteria were insensitive to pediatric migraine characteristics[14].  As a result, in this author's experience at CHOP, many pediatric neurologists do not follow ICHD criteria, and continue to use non-specific diagnoses such as Chronic Daily Headache.  In addition to these problems, clinicians report that a major barrier to correct diagnosis is lack of time in the patient interaction[2, 15].

*Improvements Tried:*
a. In 2011-12 the CHOP Primary Care Migraine Pathway was developed, and included standardized text for history-taking, treatment aids, and patient-family education documents[15].  It was designed to rule-in or rule-out migraine.  During the pilot period it was used in only 8.8% of 115 patients seen for headache by primary care physicians.  Feedback indicated it did not integrate into the workflow, took too much time, and did not address concerns about secondary headaches.  In comparison, a recent adult model showed that after integration of the ID Migraine screen into the EHR in Primary Care, the portion of patients given the non-specific diagnosis "Headache" dropped from 41% to 33%, the prescription of opioids decreased, and the prescription of triptans increased[16].  A adult headache specialist who was one of the authors of that work, will collaborate on this project.  Other decision support tools have been developed for diagnosis of adult headache, but it is unclear how widely they are used[17-22].  Furthermore, all of the adult decision support tools have

addressed only primary headache disorders, and the solution here must address the Primary Care Clinicians' worries about secondary headaches.

b. In Neurology there were 2 interventions tried simultaneously:
- The CHOP Neurology Division developed a Headache New Patient Questionnaire which incorporated concepts from the NIH Common Data Elements and other Headache Centers. Questions were reviewed for clarity and accuracy through semi-structured patient interviews. An editable PDF version of the intake form was developed and has been used to capture headache history for patients seen in the Multidisciplinary Headache Clinic since August 2013. Use of the Questionnaire addresses clinicians' concerns about limited time, but its length is viewed as burdensome to patients. In paper form it does not guide diagnosis.
- In an effort to facilitate future research projects, in Fall 2013 the Community Neurologists within the Division of CHOP Neurology created a "diagnostic cheat sheet." It was a laminated card with a standardized list of diagnostic codes and criteria.

These interventions did significantly affect the distribution of diagnoses among new patients seen for headache. Comparing the number of patients given each headache-related diagnosis in the Baseline period (January-June 2013) versus Paper Intervention period (January-June 2014), a chi-squared test yields p<0.001 (see Figure 1).

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                         InterventionGroup
    DxGrp1General      Baseline      Paper           Total
────────────────────────────────────────────────────────────
          Migraine          641        626           1,267
                          53.11      56.24           54.61
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Non-specific Headache        485        410             895
                          40.18      36.84           38.58
────────────────────────────────────────────────────────────
             Other           53         26              79
                           4.39       2.34            3.41
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       Tension-Type          28         51              79
                           2.32       4.58            3.41
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             Total        1,207      1,113           2,320
                         100.00     100.00          100.00

     Pearson chi2(3) =  18.6085    Pr = 0.000
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*Figure 1: Distribution of Headache Diagnoses by Intervention Group: In each cell the top number is the count of patients given that diagnosis, and the bottom number is the proportion of patients given that diagnosis within each column. The Baseline group was new patients seen for headache from January to June 2013, and the Paper intervention group was new patients seen for headache from January to June 2014.*

Problem #2 – Difficulty defining accurate cohort of patients: Because the diagnostic codes are frequently inaccurate as described above, manual chart review is required to assemble a cohort of patients with a particular diagnosis. This precludes large-scale QI and research projects despite the high volume of patients.

*Example:* There are ~1300 encounters in the Emergency Department and >100 patients admitted each year at CHOP for acute, severe headache refractory to outpatient treatment. Efforts to improve the care of headache at CHOP began in early 2010 with the development of the ED Migraine Pathway, with the goal of standardizing medications to decrease ED length of stay (LOS) for these patients[23]. ED Clinicians and Neurologists believe that this has been successful in decreasing length-of-stay and improving response to treatment. Building on the success of the ED pathway, in 2011 we developed a medication algorithm for inpatient treatment of headache[24]. Despite the clinicians' belief that these measures have improved care, it has not been possible to demonstrate this yet. About 70% of the children who seek care for acute, severe headache are given the diagnosis of "Headache" rather than "Migraine." Even when the more specific diagnosis of "Migraine" was used to define the cohort, patients with migrainous secondary headache (including at least one patient with a brain tumor) were included in the cohort defined by ICD-9 codes. As a result, CHOP has not yet tested the effectiveness of the ED or inpatient medication regimen. One smaller project looking at side effects of dihydroergotamine was performed with manual chart review[25].

*Barriers:* Clinicians and medical coders choose a descriptive diagnosis of Headache or Migraine without recognizing that this interferes with the ability to build a cohort of patients for quality improvement and research work.

*Improvements*: Starting in September 2014, through support from the CHOP Pathways Committee, a multidisciplinary team will formalize the Inpatient Headache Pathway and revise the ED Pathway. In parallel with the techniques discussed in this proposal, tools in EPICCare will be used to standardize data collection, guide diagnosis, and increase compliance with recommended treatments. Implementation in EPICCare will also enable metrics to be tracked for QI changes[25].

Problem #3 – Lack of documentation of Patient Reported Outcomes: Because there is inconsistency in documentation, there are no metrics by which to measure whether treatments and systemic interventions efforts have improved care.

*Example*: Neurology developed Smartphrases in EPICCare with standard language and dosing for medications, but it is not possible to measure whether this improved treatment response.

*Barrier:* Clinicians will not standardize documentation unless the new method would save time.

*Improvements tried:* The Headache New Patient Questionnaire collects baseline metrics from Neurology patients. However, this information is not stored in an extractable format, and follow-up metrics are not collected consistently. In comparison, the Cincinnati Children's (CCHMC) Headache Center has compiled a rich database which has served as the foundation for many studies, but it requires time intensive support staff data entry. In this project, the CHOP Headache Registry will build on their model, and a collaborator from CCHMC will assist in development. Patient data entry and direct availability of the data in the EHR will increase the usefulness across a wider spectrum of institutions.

The Primary Audience for this project will be Neurologists and Primary Care Providers at CHOP. Children and adolescents with headache will benefit from this project. In 2010-2011, there were 4,869 patients in Primary Care and 2,967 patients in Neurology seen for a headache-related diagnosis. As stated in the RFP, the overall prevalence of migraine in children is 7.7%.

**b. Project Design and Methods:**

**Objective 1: To create novel patient- and provider- data entry systems to focus and standardize the information collected when evaluating and following patients with headache.**

In Neurology:

1. Convert the Headache New Patient Questionnaire from paper into REDCap, a secure web-based survey application[26]. Branching logic tailors questions based on preceding answers, similar to the decision tree used by clinicians when taking a verbal history. This step was recently completed, and the form was released for patient use in the Multidisciplinary Headache Clinic starting on July 25, 2014. Semi-structured interviews in clinic and written feedback from parents have already led to revisions, and this process will continue.

   The REDCap survey is best viewed online at:
   https://tiu.research.chop.edu/redcap/redcap/surveys/?s=BRxkrCYEKj

   The survey structure is:
   Basic Demographic Information (used to link the patient back to the medical record)
   Headache History branched based on frequency of headache:
   > Pain Frequency, Duration, Location, Intensity, Quality, and Associated Symptoms
   > Provocating Factors for both individual attacks and the headache problem
   > Symptoms which could suggest Secondary Headache (provocation by Valsalva, pain waking patient from sleep)
   > Headache Disability (measured by the PedMIDAS)[27]
   > Past Headache Treatments
   Past Medical, Family, & Social History & Review of Systems
   Quality of Life (measured by the PedsQL[28, 29])

   Next steps include:
   -Conversion of patient answers into prose/table format. While REDCap is easily programmable through the web-based interface, uses branching logic, and is accessible to patients, the major limitation is that variables cannot be imported from REDCap directly into CHOP's EHR EPICCare. For clinicians who want to complete their charting in EPICCare directly, the information from REDCap that will be put into Epic must be cut and pasted. Edits made by the clinician in EPICCare to correct the patient-entered data will require manual correction in the REDCap Database.

-Review of NIH Common Data Elements and instruments from the NIH PROMIS program to ensure use of these standardized elements

2. Once the form has been refined further and is consistently and successfully used in the Multidisciplinary Headache Clinic, its use will be expanded to all new patients seen in CHOP Neurology.

3. Provider data-entry systems will be developed in REDCap. This will allow piloting and testing of the system for later development in EPICCare, and is a key step in development of the REDCap system as a stand-alone data entry system.

4. To address the limitations of REDCap and the clinicians' request to maintain their current workflow, the Patient Questionnaire will be converted from REDCap into EPICCare. A patient data entry form will be developed for the patient portals Welcome (to be used in clinic) and MyChart (to be used at home). This system has been developed at CHOP for use in asthma care[30], as depicted below in Figure 2:



*Figure 2: MyChart screenshot which shows link to MyAsthma tool*

5. A provider data entry form will be developed in EPICCare which will streamline and standardize the data collection. CHOP recently developed a similar Smartform which enables "point and click" provider data entry for patients with Inflammatory Bowel Disease as part of a multi-site Gastroenterology Registry. See below in Figure 3:

*Figure 3: Smartform for provider data entry for Inflammatory Bowel Disease Registry.*

6. Follow-up forms will be created for both patient- and provider-data entry in EPICCare. Emphasis will be placed on maximizing the ability to look at patterns over time while minimizing the amount of information which needs to be re-entered at each visit.

In Primary Care:

1. Assess the Primary Care Providers' needs and recommendations about the format in which data should be gathered.   Building on the primary care research network established at CHOP, this process began before the Letter of Intent was submitted, and has continued over the past several months.  PCPs have emphasized that the tools developed must be integrated into EPICCare, reside in their usual workflow, and fit the time constraints of typical visits (15 minutes).  Furthermore, given the tremendous size of the CHOP Care Network, they prefer to adapt a system which has been proven to be effective in another setting rather than participate in development from scratch. Therefore, while the data entry system is developed and implemented in Neurology, feedback will be gathered through a formal review process by the Primary Care Advisory Council (PCAC) and Pediatric Research Consortium (PeRC).

2. Use factor analysis of the Neurology intake forms to determine which questions are needed to ensure that both dangerous secondary causes of headaches and primary headache disorders can be identified.  "Short Forms" will be created for primary care.

3. Work with the Care Network to initialize a pilot study of implementation of the "Short Forms."  The pilot study will be conducted as a future study.

**Objective 2: To synthesize the available evidence and the diagnostic criteria from the International Classification of Headache Disorders into point-of-care Clinical Decision Support tools to guide diagnosis and management of headache.**
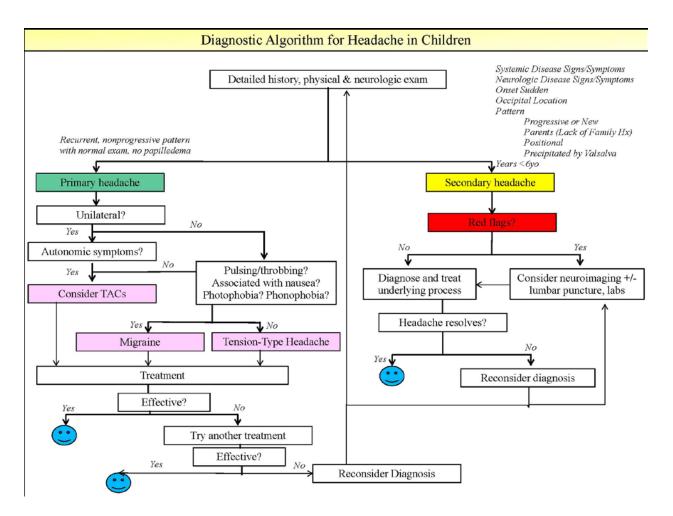
In Neurology:

1. Starting in REDCap, diagnostic algorithms will be designed to identify secondary headaches and primary headaches based on ICHD criteria (ICHD-II for now, with ability to test ICHD-IIIβ as well). For the general framework used please see below Figure 4.

2. Evidence-based algorithms will be developed for the evaluation and treatment of different types of headache. The available Practice Parameter from 2002 on evaluation of recurrent headaches will be used[13], and the literature will be reviewed for relevant publications since that time. The algorithms will include guidance on imaging, emergent referrals, criteria for use of preventive treatments for migraine, and options for migraine treatment. These will be developed in REDCap and later implemented in Epic.

3. Once the provider data entry Smartform has been developed as described above under Objective 1, the diagnostic algorithms will be modified to include exam findings and other provider-entered data.

4. Algorithms will be converted to Clinical Decision Support tools at the Point-of-Care. The tools will incorporate the features associated with successful implementation as outlined by the Agency for Healthcare Research & Quality[3].

5. The diagnostic algorithms will be validated in comparison to expert opinion to ensure that the sensitivity for migraine matches prior comparisons between ICHD-II appendix criteria and clinical diagnosis[14].


In Primary care:

1. Modify the diagnostic, evaluation, and treatment algorithms for primary care in response to workflow issues and diagnostic questions as they arise.

2. Modify the Clinical Decision Support tools to match those algorithms.

3. Gather feedback on the usefulness and perceived appropriateness of these tools from PeRC network.

*Figure 4: Algorithm for the Diagnosis of Headache in Children*

**Objective 3: To develop a Pediatric Headache Registry using the EHR at CHOP as a platform for a future National Pediatric Headache Registry.**

1. Continual evaluation and revisions during development and testing of the data entry systems will ensure that they have been programmed to maximize both ease of clinician use and ability to retrieve data for QI/research.

2. In order to enhance identification of cohorts of patients with specific headache diagnoses, a marker of use will be built into the patient- and provider- data entry systems in EPICCare to enable tracking and comparison with ICD diagnostic codes.

3. During development and testing this model will be presented to the Pediatric & Adolescent Section of the American Headache Society to gather feedback bi-annually. The Executive Committee and Chair of the Pediatric & Adolescent Section, along with several members have expressed interest in collaborating.

4. After single site development of the REDCap system at CHOP, the database will be made available for use in a multisite environment. For providers at external institutions which use their own version of REDCap, the database will be copied by sharing the list of

variables and parameters, called the data dictionary.  These providers will then be able to use all surveys and decision support tools in their own version of REDCap.  All institutions will later be able to merge de-identified data easily since the data structure will be the same.  For providers who do not have access to REDCap at their own institutions (including clinicians in private practice), they can request an account for CHOP REDCap.  They will be assigned to a Data Access Group which will enable them to see all of the surveys and tools relevant to their own patients.  When data is exported from the database, patient identifiers will be removed.  In this way, multiple clinicians can use the forms for patient care, but privacy will be maintained for data extraction and analysis.

5. In addition, to meet the needs of clinicians who prefer that the data collection and decision support system be housed within the existing EHR, the EPICCare version will be piloted at one other site.  EPICCare is the most common EHR vendor among hospitals with 200+ beds, so the system will be translatable to many institutions across the country[5].  While the details of the collaboration have not yet been solidified, several colleagues at institutions which use EPICCare have expressed interest.   Funds for informatics and travel have been set aside in the budget.   The Inflammatory Bowel Disease Registry which was developed at CHOP and expanded to multiple institutions will serve as precedent.  Clinicians and programmers involved in that project at CHOP have agreed to advise this project. Translating the platform to another site will clarify the amount of time and money that will be required to adapt the system into a multi-center National Pediatric Headache Registry.  By testing both the REDCap and EPICCare platforms we will be able to discern whether one system is more easily used than the other, or whether the two are complementary.  With future grant support, this robust model could be implemented at multiple institutions to build the Registry, and the system could also be adapted for adult headache.

**c. Evaluation Design:**
As described above in the needs assessment, past work at CHOP has highlighted the following problems:

1. Inaccurate <u>diagnosis</u>
2. Difficulty defining accurate <u>cohort</u> of patients
3. Lack of documentation of <u>Patient Reported Outcomes</u>

The project will be evaluated on the following metrics:

1. Rate of <u>diagnosis </u>of migraine in Outpatient Neurology:  The goal will be an increase of 5% in the portion of headache patients diagnosed with migraine in Neurology from before to after implementation of the data entry and decision support tools in EPICCare.

Specifically, patients given the diagnostic codes 307.81, 339.xx, 346.xx or 784.xx will be extracted from EPICCare by the Clinical Reporting Unit of the Center for Biomedical Informatics.  Analysis will be performed by the PI and the statistician from the Biostatistics & Data Management Core (BDMC) using STATA.  The primary comparison will be the portion of headache patients diagnosed with migraine in the Paper period (i.e., the system currently in place before starting the work of this grant) versus the Epic period as defined below.  Secondary analysis with X-square testing will compare distribution of diagnoses among all time periods, defined as:

   a. The Baseline Period - January to June 2013, a time before any diagnostic interventions had been implemented.  Analysis described above demonstrated that 53.11% of new headache patients were given a diagnosis of migraine in this period.

   b. The Paper Period - January to June 2014, when providers were given a laminated card with lists of diagnoses and encouraged to use the most specific diagnosis possible (i.e., Intractable Chronic Migraine rather than Chronic Daily Headache).  During this period the paper and Adobe PDF versions of the New Patient Questionnaires were used for some patients.  Analysis described above demonstrated that 56.24% of new headache patients were given a diagnosis of migraine in this period.

   c. The REDCap Period - January to June 2015, when the New Patient Questionnaire will be implemented in REDCap and providers will have the headache history copied into Epic.

   d. The Epic Period – January to June 2016, when patient and provider data entry will be completed in EPICCare and decision support tools in EPICCare will guide diagnosis, evaluation, and treatment.

Given the relatively wide range in the portion of patients diagnosed with migraine in the pediatric clinic-based cohorts described above, it is somewhat difficult to predict the portion of patients seen in CHOP Neurology who actually have migraine.  The closest prediction can be made by examining the diagnoses in new patients evaluated by the providers in the Multidisciplinary Headache Clinic.  Among all new patients seen since July of 2012, 581 were seen by a Headache Clinic provider.  Within that group, about 63% were given a diagnosis of migraine.  Because the Headache Clinic includes a higher number of patients referred for second opinions with refractory primary headache disorders, it is appropriate to assume that the portion of patients with a secondary headache may be slightly higher in general neurology.  As such, the goal portion of patients with diagnosis of migraine will be 61.24%, representing an additional 5% increase over the Paper intervention group.

Because the providers in the division of Neurology share patients and work closely together on quality improvement projects, if patients or providers were divided into control and intervention groups there would be contamination between the groups.

Furthermore, the goal is to achieve improvement in known measures, which make a pre- and post-intervention comparison appropriate.

2. Ability to define accurate <u>cohort</u> of patients: A marker of use will be included in the patient- and provider-data entry tools to define the cohort of patients evaluated for headache.  In the subset of that cohort seen by one of the Headache Clinic providers, the sensitivity and specificity of the ICD9 diagnoses "Headache (784.0)" and "Migraine (346.xx)" will be calculated as compared against the gold standard of expert opinion.

3. Documentation of <u>Patient Reported Outcomes</u>:  The portion of encounters with documented pain severity and headache frequency will be tracked over time.  The goal will be measurement of these variables in 80% of encounters within 6 months of implementation of the follow-up form.

Measuring engagement of the target audience:

1. Rate of use of the data entry tools will be measured as the portion of encounters where each tool is used compared with all encounters for headache.

2. Patient and provider satisfaction with data entry tools will be measured with a Likert scale.  Baseline data will be collected at the start of the project before the data entry tools are put into Epic, and follow-up data will be collected after the tools have been implemented.

3. Portion of headache patient charts closed more than 5 days after encounter will be measured.  Baseline data will be collected at the start of the project before the data entry tools are put into Epic, and follow-up data will be collected after the tools have been implemented.

4. Feedback will be gathered at routine Headache Program and Community Neurology meetings.

5. In Primary Care, the model will be discussed extensively with the Pediatric Research Consortium before proceeding with pilot implementation.


The project outcomes will be disseminated through publication and presentation of this work at meetings of the American Headache Society.  In addition, once it has been fully developed and implemented at CHOP, the REDCap database will be shared with members of the AHS Pediatric & Adolescent Headache Section.  The Epic data entry forms and decision support tools will be implemented at 1 pilot site to gauge future feasibility.


**3. Detailed Workplan and Deliverables Schedule:**

**Project Timeline** Across the 2 years, the project will be presented and feedback will be solicited from the AHS Pediatric & Adolescent Section biannually
<u>Neurology:</u>

*Month 1-6:* Develop data entry system in REDCap. Implement in Headache Program, then all Neurology. Design diagnostic, evaluation, and treatment algorithms and implement in REDCap as decision support tools.

*Months 7-12*: Develop and implement data entry systems in Epic. Share REDCap database with pilot sites through the AHS.

*Months 13-18*: Develop and implement Clinical Decision Support tools in Epic. Share REDCap database more broadly through the AHS.

*Months 19-24*: Collect and analyze data on CHOP cohort. Validate diagnostic decision support tool. Implement program at 1 other site.

Primary Care:

Month 1-12: Work with Pediatric Research Consortium to develop framework.

Months 13-18: Adapt data entry system for use in Primary Care

Months 19-24: Adapt Clinical Decision Support tools for use in Primary Care and prepare for Pilot implementation.

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Detailed Schedule of Deliverables:

| Schedule | Deliverable |
| --- | --- |
| Oct 2014 | Neurology - Complete development of New Patient Questionnaire in REDCap, including addition of PROMIS measures and piping of variables for use in Epic. |
| Oct –Nov 2014 | Neurology - Design diagnostic algorithm and model in REDCap as decision support tool |
| Oct 2014 – Sept 2015 | Primary Care - Work with Pediatric Research Consortium to determine best framework for data entry and decision support tools |
| Nov 2014 | Neurology - Complete implementation of REDCap New Patient Questionnaire in Headache Program |
| Nov 2014 | Neurology - Develop provider data entry system (exam, diagnoses) in REDCap |
| Nov 2014 | Gather feedback from AHS Pediatric & Adolescent Section at the Scottsdale Headache Symposium |
| Nov 2014 – Mar 2015 | Neurology - Modify REDCap New Patient Questionnaire based on feedback from semi-structured interviews |
| Dec 2014 | Neurology - Implement REDCap New Patient Questionnaire across Neurology |
| Dec 2014 – Jan 2015 | Neurology - Design evaluation algorithm and model in REDCap as decision support tool |
| Jan - Jun 2015 | Neurology – Collect diagnostic data for the "REDCap period," i.e. the time when New Patient Questionnaire has been implemented (patient completing in REDCap, information copied into Epic) but Epic data entry and decision support tools are not yet in place |
| Jan – Mar 2015 | Neurology - Develop patient and provider data entry systems for follow-up visits in REDCap |
| Feb – Mar 2015 | Neurology - Design treatment algorithm and model in REDCap as decision support tool |
| Apr – Jul 2015 | Neurology - Develop patient and provider data entry systems for follow-up and new visits in Epic |
| Jun 2015 | Gather feedback from AHS Pediatric & Adolescent Section at AHS Scientific Meeting |
| Jul 2015 | Share REDCap database with few pilot sites through AHS |
| Aug-Sept 2015 | Neurology - Implement patient and provider data entry systems in Epic and revise based on feedback |
| Oct-Nov 2015 | Neurology - Develop and implement Clinical Decision Support tools in Epic from algorithms described above |
| Nov 2015 | Gather feedback from AHS Pediatric & Adolescent Section at Scottsdale Headache Symposium |
| Dec 2015 | Share REDCap database for general use through AHS |
| Dec 2015 – May 2016 | Primary Care - Adapt Clinical Decision Support tools |
| Jan – Jun 2016 | Neurology – Collect diagnostic data for the "Epic period," the time when patient and provider data-entry and decision support tools have been implemented in EPICCare |

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| Jan – Jun 2016 | Neurology - Validate diagnostic decision support tools |
| June 2016 | Gather feedback from AHS Pediatric & Adolescent Section at AHS Scientific Meeting |
| Jul – Sep 2016 | Neurology - Analyze data and prepare publication |
| Jun – Sep 2016 | Neurology – Implement program at 1 other site and apply for additional funding for dissemination to other sites |
| Jun – Sep 2016 | Primary Care – Adapt patient- and provider- data entry systems to develop "Short Forms", prepare for Pilot Implementation |