“Data Management for EHDI: Helpful Friend, Not Dreaded Foe—Continued”

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It’s as easy as “1 – 3 – 6”?

- Percentage of all newborn infants who complete screening by 1 month of age.
- Percentage of newborns who have been screened for hearing before hospital discharge.
- Documented Passed and Not Passed the final (last or most recent) screen.
It’s as easy as “1 – 3 – 6”?

• Not screened at hospital
  – missed, equipment failures, home births

• Fail initial screen with no documented 2nd screen
  – protocol driven, 1 stage/2 stage, closed cases vs. lost
  – fail final (most recent) screen with no documented audiological diagnosis

• Diagnosis not completed due to multiple visits
  – OME complications, sedation issues

• Identified infant with hearing loss to intervention
  – referral or enrolled
How do you get your data to answer these questions?
How do you get your data?

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How do you get your data?

- What questions or answers (data) do you want to collect?
  - Newborn Screening Results only
  - More comprehensive with many providers linking data from multiple encounters
  - Required reporting by hospital, state or other agencies
How do you get your data?

- Teamwork – at hospital, state and/or regional level
  - Including resource people available (i.e., IT)

- Clearly defined protocols
  i.e., how do you define a hearing “refer”?
  - Literature or Other Program Reviews – data based decisions
How do you get your data?

• Documentation
  – Document protocols and definitions, document process (how you enter the data, or when you report, or how to link data etc.), document the data definitions and formats. And it goes on & on, document, document, document, document!

• Training

• Remember just because there is a protocol doesn’t mean it is being followed
  - easy to understand and follow
  - the more people on the same page the better – it they own the process
How do you get your data?

• **How to gather the data?**
  
  • Paper forms / sent or fax or email back – somewhere resources are needed to convert to electronic data
  
  • Electronic file sent – challenges how define fields etc, more IT resources, data only comes incrementally (home grown or purchased software)
  
  • Web based entry – centralized saves on IT resources, but missing data can become a problem
  
  • Linkage of differing systems and data programs (i.e. in-house hospital system, hi-track, and a paper based system)
How do you get your data?

- How to gather the data?
- High tech does not mean better data!!

- Web based approaches will not be any better than a fax back paper system if the essential questions/data are not collected and the people providing the information are not trained on the goals and how to use the data system!
Dimensions of Data Quality

Data Quality

Completeness

Accuracy

Consistency

Timeliness

Validity

Integrity
**Dimensions of Data Quality**

Completeness

- Data are **complete**
  - Contains all necessary data fields
  - No errors of omission (missing data)

Accuracy

- Data are **correct**
  - No errors of commission (data entry)
  - No errors of format or logic
  - Data are unduplicated
Dimensions of Data Quality

Validity

Data are true & credible

☑ Data sources/Source documents

Timeliness

Data are current

Timeliness is affected by: (1) the rate at which the program’s information system is updated; (2) the rate of change of actual program activities; and (3) when the information is actually used or required
Dimensions of Data Quality

Consistency

Data are consistent across multiple data sets
✓ No conflicting information (inconsistencies) about same data value

Integrity

Data are correctly joined together across multiple data sets; data documentation kept
Integrity is also when data generated by a program’s information system are protected from deliberate political or personal bias or manipulation
Ensuring Effective Data

• Data are complete
  – Complete files (no records are missing)
  – Complete records (all fields are known for each record)

• Data are correct
  – Understand data definitions and apply consistently
  – Capture data electronically (screening device/demographics)
  – Drop down menus (decreases mis-coding)
  – Calculation checks for outliers (e.g. minimum/maximum or erroneous dates)
Ensuring Effective Data

- Data are not duplicated
  - De-duplication software (data cleaning)
  - Manual audits/edits
Ensuring Effective Data

Data cleaning framework:
- Search and identify error instances
- Correct the errors
- Document and define error types
- Modify data entry procedures to reduce future errors

Error prevention is far superior to error detection
Documenting Quality Data

- Manual chart reviews (original source)
- Maintain an audit trail
- Document metadata
Data Storage

- Backup Plan
- Recovery Plan
- Archiving Plan
- Disposal Plan
Questions & Discussion

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