

Tuesday, October 20, 1:30-3:00 PM

Concurrent Breakout Session C3

NBDPN Standards Data Quality Tools - Data Quality Performance Measures

- * Results of the 2015 NBDPN Data Quality Assessment
- * Assessing the Quality of Data from the FL Birth Defects Registry: Completeness, Accuracy, Timeliness
- * Implementing a Quality Improvement Approach to Enhance Birth Defects Surveillance in MA
- * State Sharing and Discussion

Results of the 2015 NBDPN Data Quality Assessment

Marlene Anderka, ScD, MPH

For the SGSC Standards Work Group

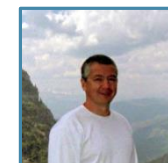
NBDPN Annual Meeting

October 20, 2015



Surveillance Guidelines and Standards Committee Standards Work Group

- AR: Bridget Mosley
- CDC: Cara Mai, Richard Olney, Jennifer Isenburg
- CO: Russel Rickard, Carol Stanton
- FL: Russell Kirby
- IA: Paul Romitti
- MA: Marlene Anderka (Chair)
- MI: Glenn Copeland
- TX: Mark Canfield
- UT: Marcia Feldkamp
Sergey Krikov



Agenda

- 2015 Data Quality Assessment Tool
- Results of Data Quality Assessment – Year 2
- Next Steps to Improve Data Quality

Data Quality Assessment Tool

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Standard Levels

Performance 

Level 1

- Below the norm
- RUDIMENTARY

Level 2

- Where the majority of programs will fall
- ESSENTIAL

Level 3

- Above the norm
- OPTIMAL

Example of a Data Quality Measure

Completeness DQ1.3	DQ1.3 Pregnancy outcomes included	Level 1	Level 2	Level 3	
	<p>This indicator identifies the types of pregnancy outcome categories in the surveillance data base, regardless of data sources.</p> <p>Reference: Chapters 3 and 12</p> <p>Please check the highest performance level that applies.</p>				
	<p>None or Unable to achieve level 1 (Please explain in comment box)</p>		<input type="radio"/>		
	<p>Level 1 Live births</p>		<input type="radio"/>		
	<p>Level 2 Live births, stillbirths¹ (fetal deaths at ≥ 20 weeks EGA² OR >350 grams if EGA is not available)</p>			<input type="radio"/>	
	<p>Level 3 Live births, stillbirths¹ (fetal deaths at ≥ 20 weeks EGA² OR >350 grams if EGA is not available), and other pregnancy loss, e.g. induced terminations</p>				<input type="radio"/>
<p>Comments:</p> <div style="background-color: #e6f2ff; height: 80px; border: 1px solid #ccc;"></div>					
<p>¹ Programs may identify stillbirths from a variety of data sources, e.g. death certificates, hospital reports, pathology reports, etc.</p> <p>² EGA = estimated gestational age. Gestational age may be derived in various ways (including last menstrual period, physician prenatal estimate, postnatal exam, etc.). The NBDPN Birth Defects Surveillance Guidelines and Standards Chapter 3 gives a hierarchy of the accuracy of these methods. Programs should employ this hierarchy to use the most accurate method for including EGA in surveillance data.</p>					

Differences between 2014 and 2015 Data Quality Assessments

Associated Documents

- * [Appendix 3.1 Birth Defects Descriptions for NBDPN Core, Recommended, and Extended Conditions](#) (this replaces old appendices 3.1 & 3.2)
- * [Appendix 4.1 Descriptions of NBDPN Data Elements for Population-based Birth Defects Surveillance](#) (this replaces old appendices 4.1 & 4.2) - Updated 3/2015

Assessment Tool

- * Slight rewording of a few performance level criteria to match language in revised lists of birth defects and data elements

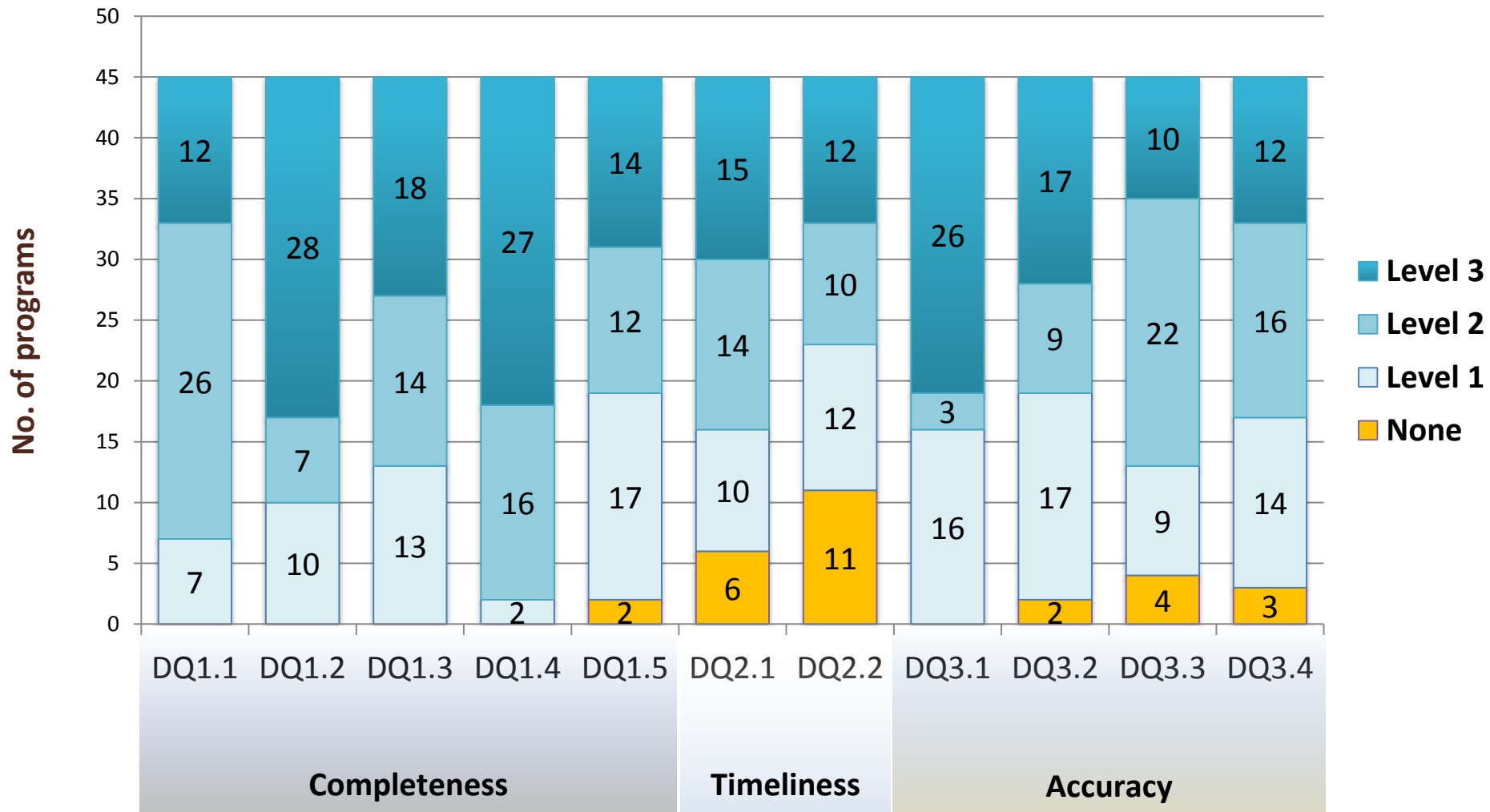
Overview of Data Quality Standards Assessment Rollouts

	2014	2015
Eligible Programs*	47	47
Surveys Submitted	45	47
Surveys Excluded**	2	2
# Active Case Finding Responders	17	17
# Passive Case Finding Responders	26	28
# Total Programs Included	43	45

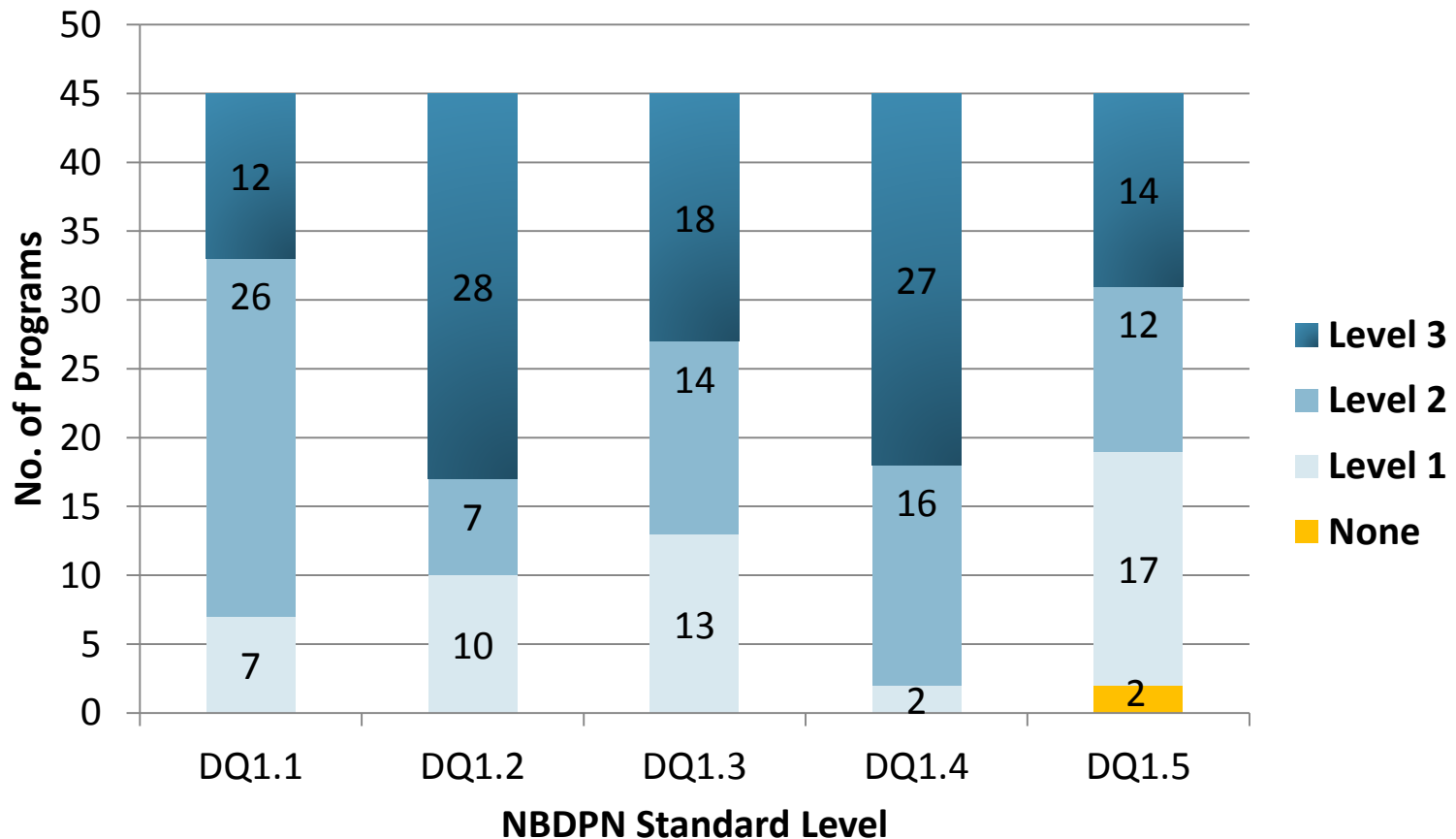
***Programs with population-birth defects surveillance - includes 44 states, DOD, CDC and Puerto Rico.**

****Programs not meeting level one on Measure 1.1 or not achieving and overall average score of 1.**

2015 Results: All Performance Measures

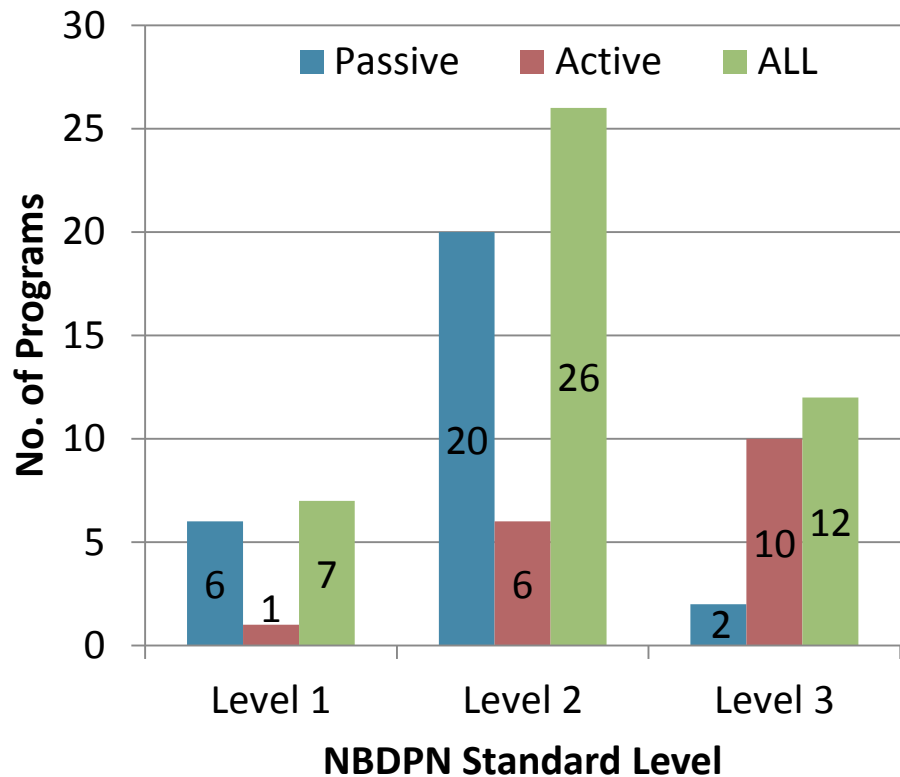


Completeness Measures



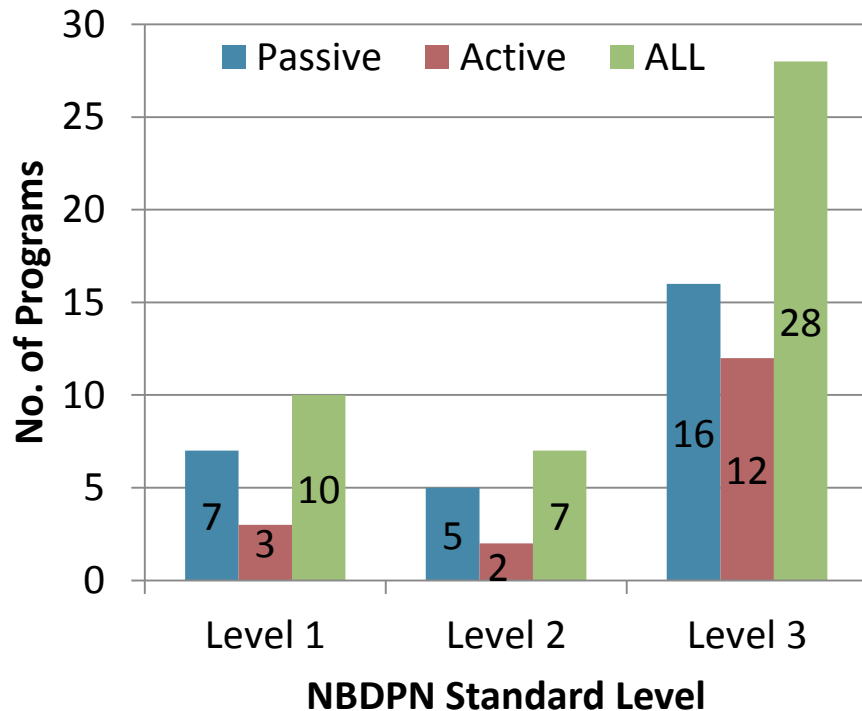
- Measure the degree to which data are all-inclusive and comprehensive
- Assess data sources for case ascertainment, ages of cases ascertained, and the birth defects, pregnancy outcomes, and data elements included

DQ 1.1: Types of data sources used systematically and routinely to ID potential cases at a population-based level



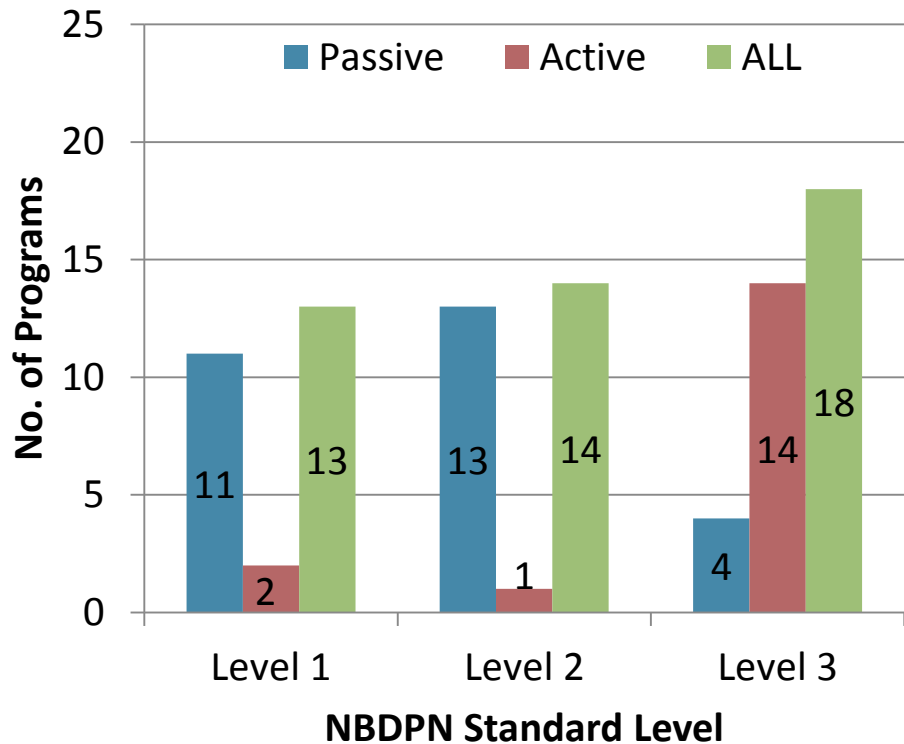
- L1: VR + one other data source
- L2: One additional source beyond L1
- L3: Sources beyond L1 and L2, e.g. diagnostic centers
- Goal: Cast a wide net to ascertain as many cases as possible
- 84% of programs at \geq Level 2
- 79% of passive and 94% of active case-finding programs at \geq L2

DQ 1.2: Birth Defects included using standard NBDPN case definitions



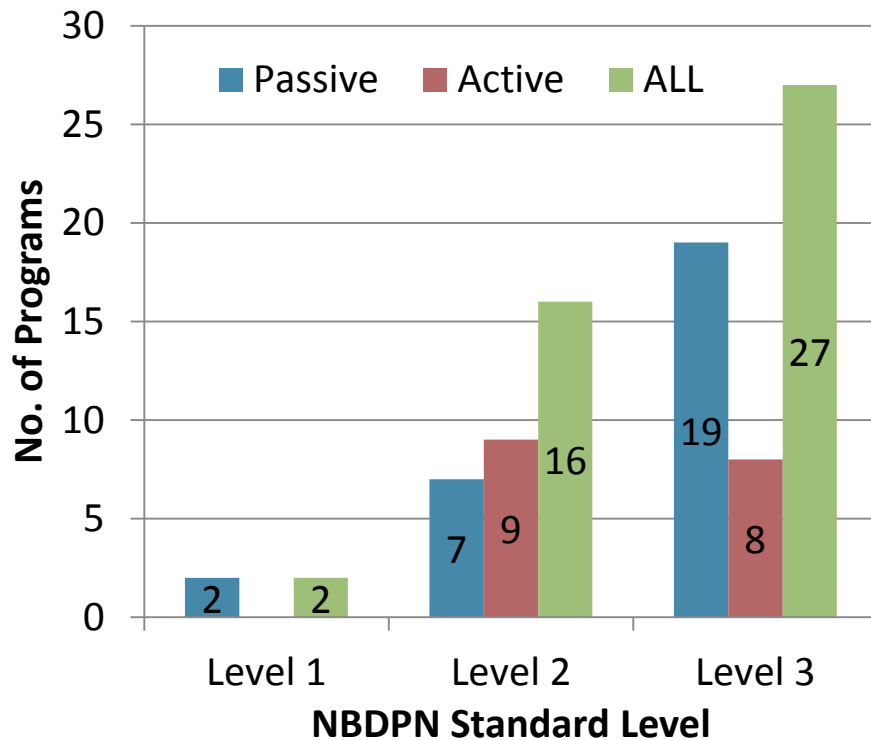
- L1: All NBDPN “core” birth defects
- L2: All NBDPN “recommended” birth defects
- L3: All conditions on the NBDPN list including “core”, “recommended” and “extended” plus birth defects beyond the list
- 78% of programs at \geq Level 2
- 75% of passive and 82% of active case-finding programs at \geq L2
- Revised birth defects list can be used by programs as a guide

DQ 1.3: Pregnancy outcomes included



- L1: Live births
- L2: Live births plus stillbirths
- L3: Live births, stillbirths and other pregnancy losses
- 71% of programs \geq Level 2
- 61% of passive and 88% of active case-finding programs at \geq L2

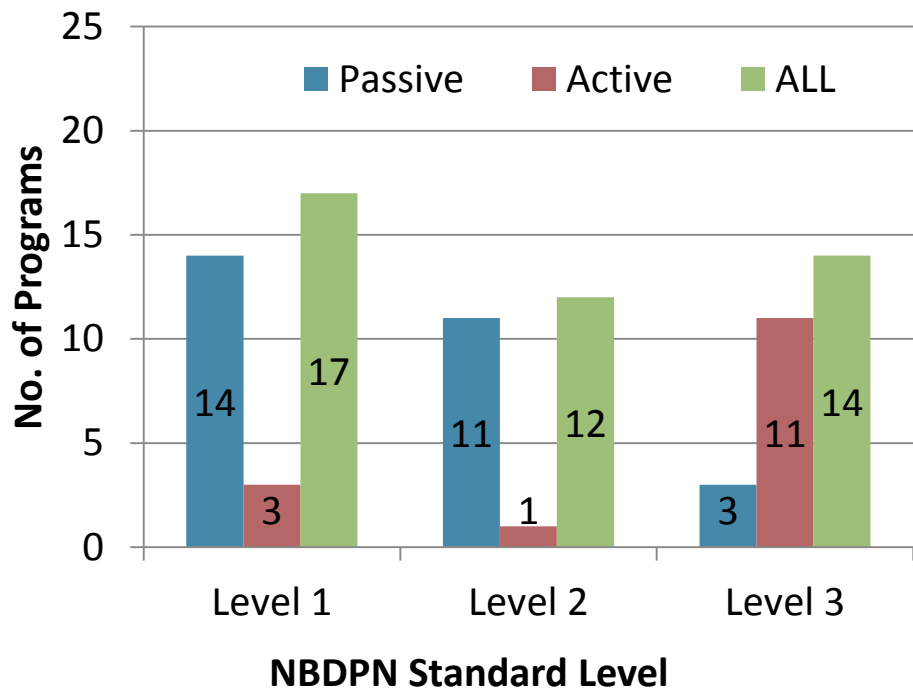
DQ 1.4: Systematic and routine identification of cases during ascertainment period (age of diagnosis)



- L1: cases diagnosed through 1 mo
- L2: cases diagnosed through 1 yr
- L3: cases diagnosed beyond 1 yr

- 96% of programs at \geq Level 2
- 93% of passive and 100% of active case-finding programs at \geq L2

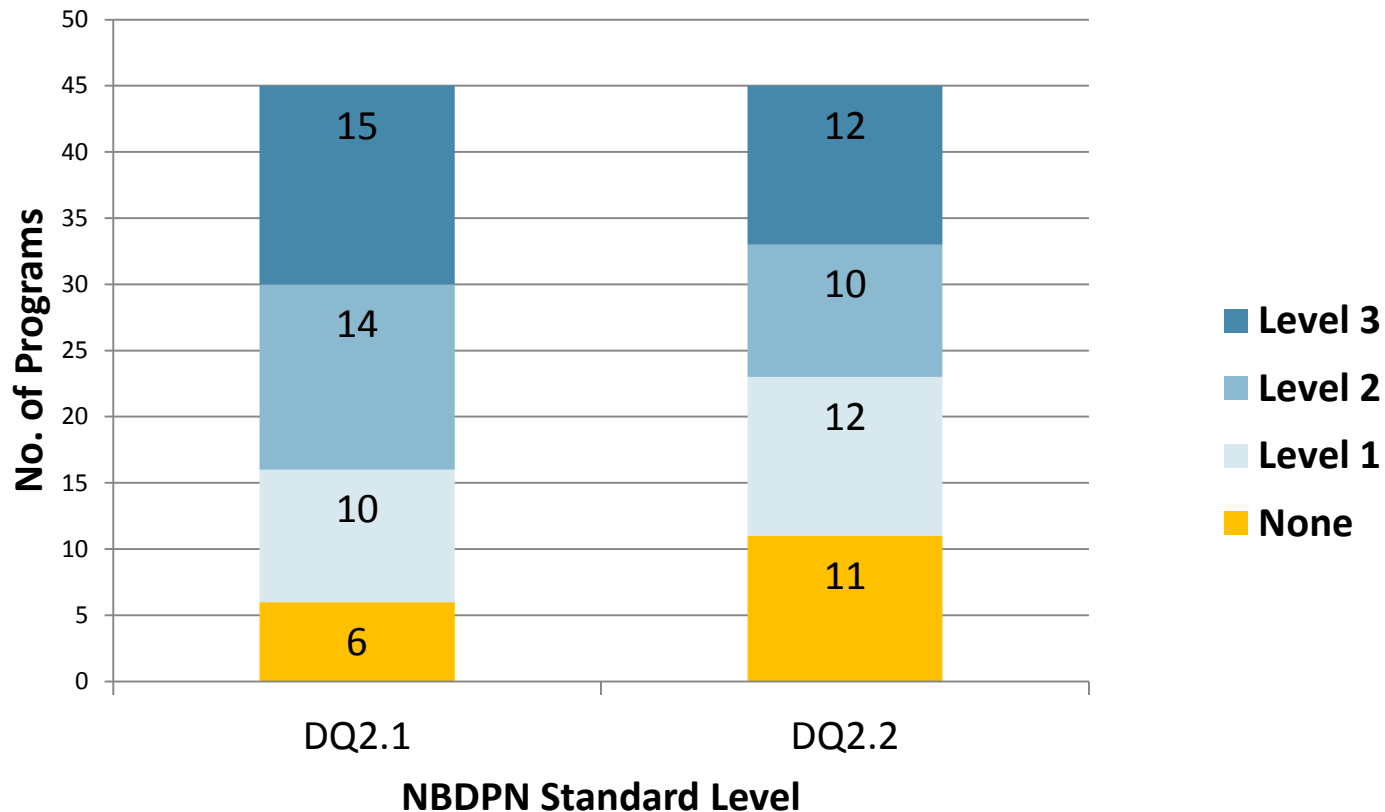
DQ 1.5: Data elements collected



Frequency unable to achieve level 1 = 2

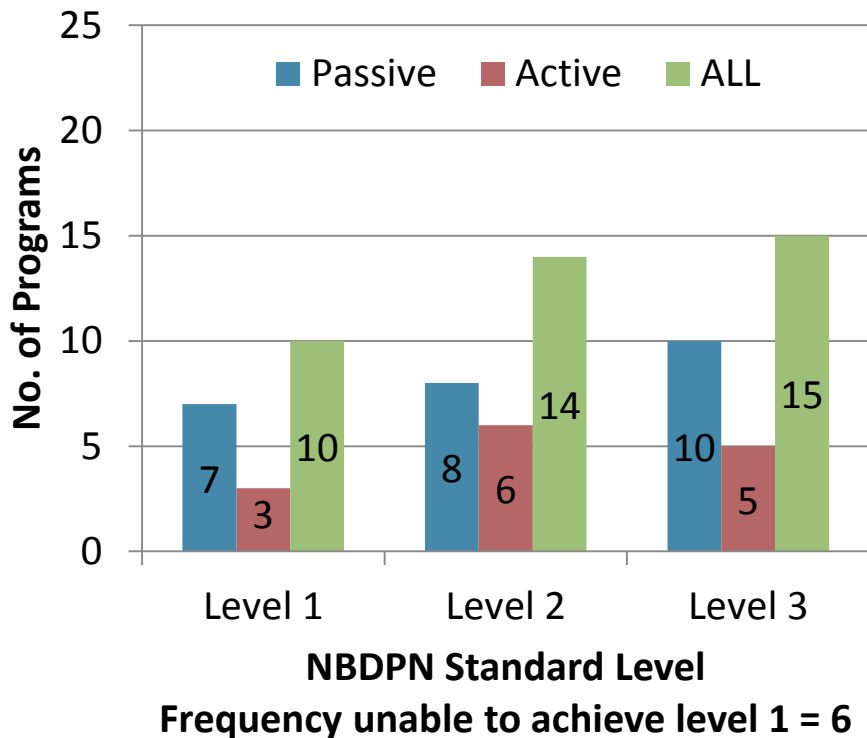
- L1: all level 1 data elements
- L2: all levels 1 and 2 data elements
- L3: all Level 1, 2 and 3 data elements and beyond
- Collected = “collect or access to”
- 42% of programs at <L2 (includes 2 programs unable to achieve L1)
- 50% of passive and 29% of active case-finding programs at < L2
- Revised data elements list can be used by programs as a guide

Timeliness Measures



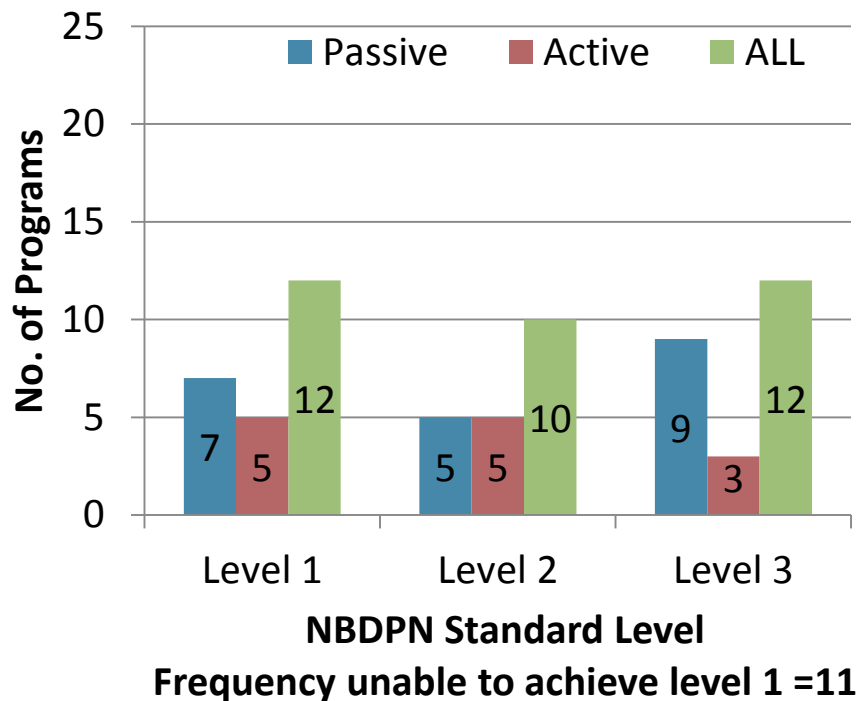
- Measure the extent to which data are rapid, prompt and responsive
- Assess timeliness of data on birth defects from the 'core' and 'recommended' lists

DQ 2.1: Time of case data completion for NBDPN “core” defects



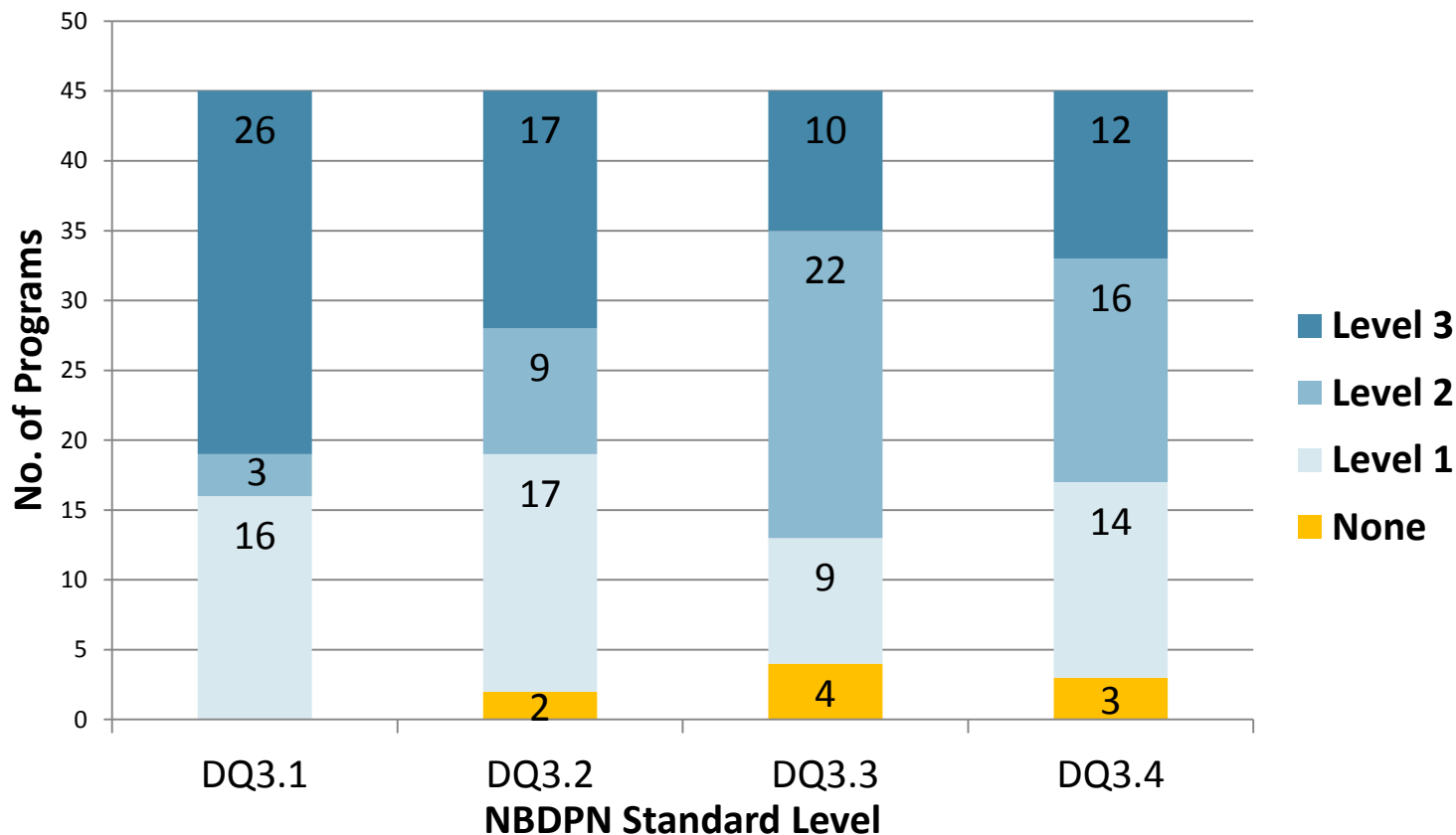
- L1: 75%+ core BD w/in 2 yrs
- L2: 95%+ core BD w/in 2 yrs
- L3: 99%+ core BD w/in 2 yrs
- 36% of programs were <L2 (includes 6 programs unable to achieve L1)
- 36% of passive and 35% of active case-finding programs at < L2
- Explore various tools and methods to monitor timeliness
- Explore defining timeliness by use, e.g. defining timeliness measure to coincide with the NBDPN data call

DQ 2.2: Time of case data completion for NBDPN “recommended” defects



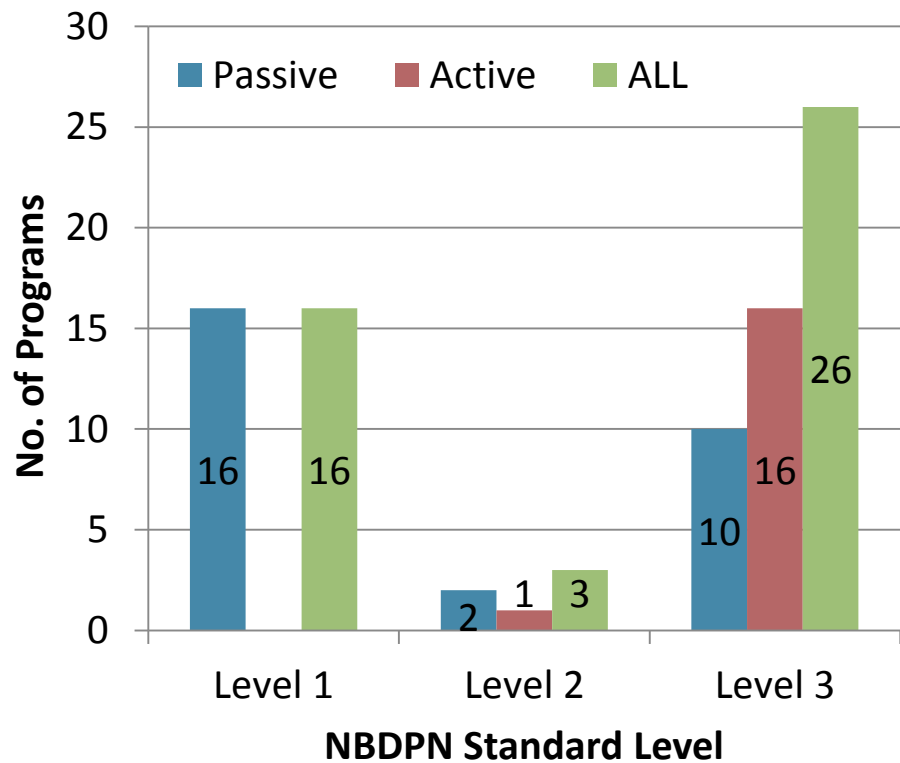
- L1: 75%+ recommended BD w/in 2 yrs
- L2: 95%+ recommended BD w/in 2 yrs
- L3: 99%+ recommended BD w/in 2 yrs
- 51% of programs were <L2 (includes 11 programs unable to achieve L1)
- 50% of passive and 53% of active case-finding programs at < L2
- Explore various tools and methods to monitor timeliness
- Explore defining timeliness by use, e.g. defining timeliness measure to coincide with the NBDPN data call

Accuracy Measures



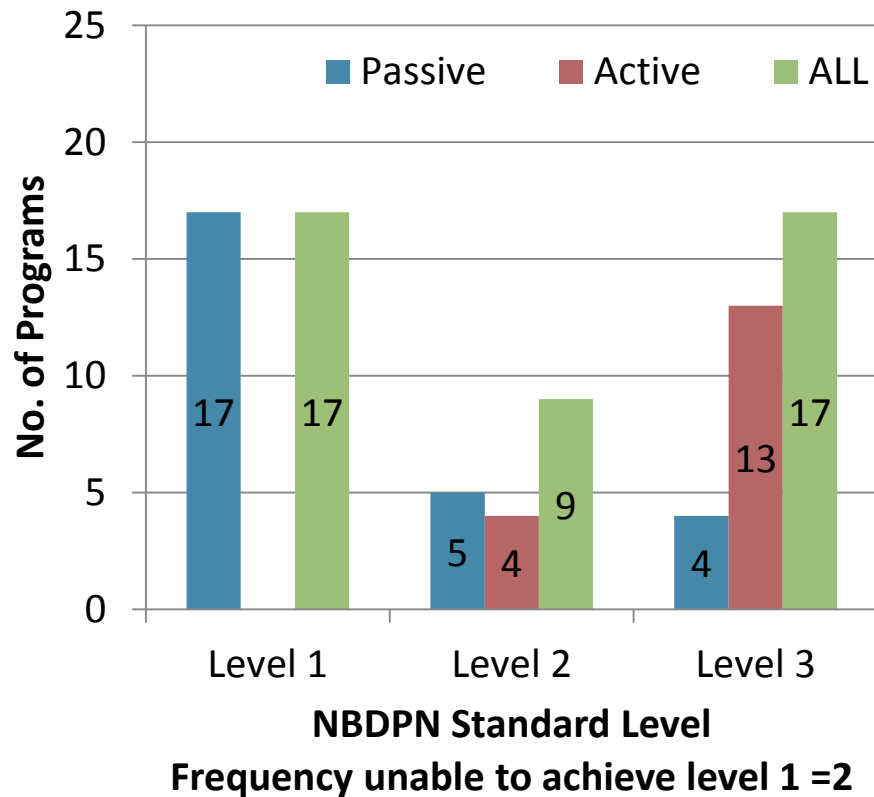
- Measure the extent to which data are exact, correct and valid
- Assess methods for verification of case diagnosis, birth defects verified, expertise of individual performing verification, and database quality procedures for data elements

DQ 3.1: Data quality procedures for verification of case diagnoses



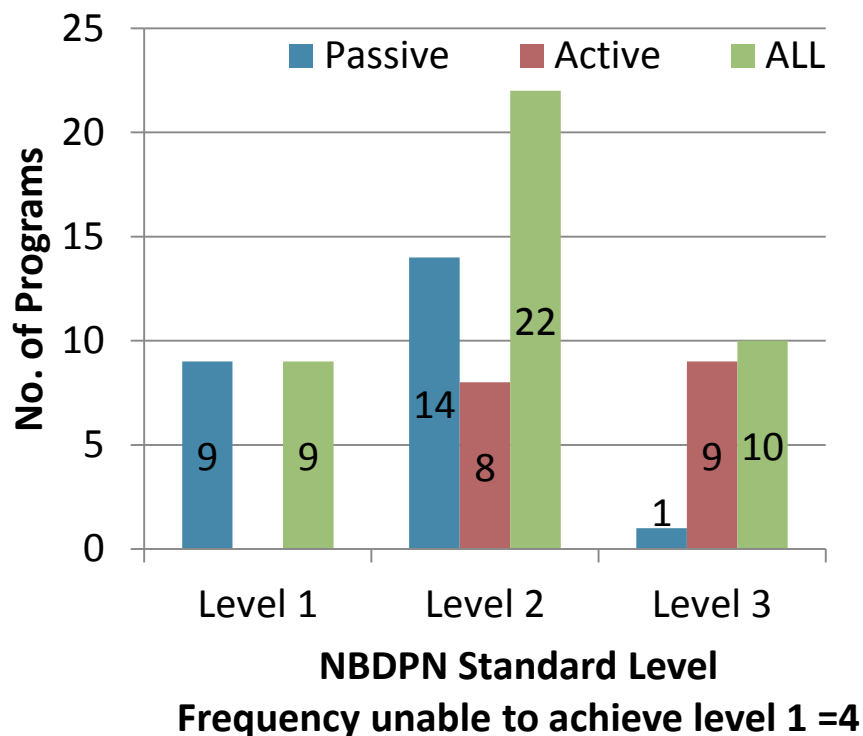
- L1: Minimal procedures
- L2: Verification using some method
- L3: Verification beyond L2
- The mean level for passive case-finding programs was 1.8 vs 2.9 for active programs
- 57% of passive and no active case-finding programs at < L2
- Verification, not validation
- Explore improvements for those that use administrative data sets, e.g. verification via lab reports

DQ 3.2: Scope of birth defects verified



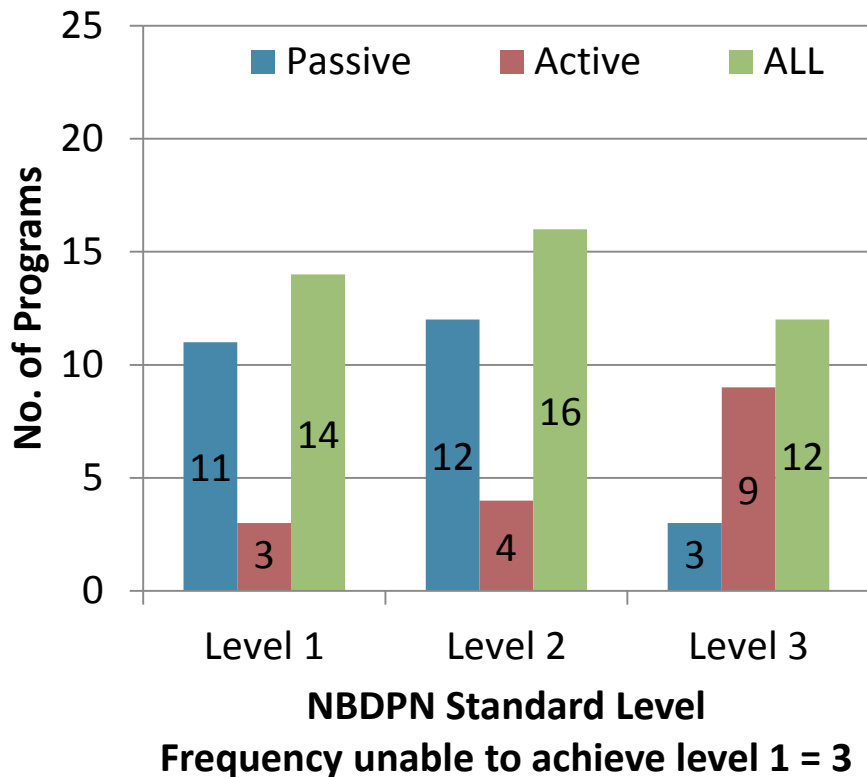
- L1: Special projects, selected diagnoses or samples
- L2: All core BD
- L3: All recommended BD
- The mean level for passive case-finding programs was 1.4 vs 2.8 for active programs
- 68% of passive and no active case-finding programs at < L2
- Explore improvements for those that use administrative data sets, e.g. verification via lab reports

DQ 3.3: Level of expertise for individual who performs case diagnosis verification



- L1: Minimal disease coding or clinical expertise
- L2: Expertise in disease coding or clinical training
- L3: High level expert
- The mean level for passive case-finding programs was 1.4 vs 2.5 for active programs
- 46% of passive and no active case-finding programs at < L2

DQ 3.4: Database quality assurance process



- L1: QC for core data elements
- L2: QC for recommended data elements
- L3: QC for extended data elements
- The mean level for passive case-finding programs was 1.6 vs 2.2 for active programs
- 46% of passive and 23% active case-finding programs at < L2
- Revised data elements list identifies specific data quality checks as a guide for programs

National Efforts to Improve Data Quality

NBDPN Standards Group will:

- Provide each site a report of their scores compared to the overall average scores
- Incorporate Standards into the Surveillance Guidelines manual
- Conduct ongoing reassessment and improvement

Program Efforts to Improve Data Quality

- Prioritize NBDPN standards
- Put processes in place to assist with achieving national standards
- Serve as champions raising awareness about the value of national standards
- Articulate need for resources to achieve national standards at your site



Questions?

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