

Effective, Ethical, and High-Quality Use of Healthcare Data

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MHA 621
Healthcare Informatics

Lecture 2



Intended Learning Outcomes

- **By the end of this lecture, you should be able to:**
1. **Explain why healthcare data quality matters.**
 2. **Describe the main parts of data quality.**
 3. **Explain data governance and data provenance.**
 4. **Discuss privacy, confidentiality, consent, and patient rights.**
 5. **Identify ethical risks in analytics and Artificial Intelligence.**

Lecture Roadmap



1. Data Quality and Data Governance



3. Privacy, Confidentiality, and Patient Autonomy



Healthcare Data and Business Intelligence



2. Responsible Use of Healthcare Data



4. Bias, Fairness, Accuracy, and Human Oversight



AI: Artificial Intelligence

BI: Business Intelligence



1.



C&BI: Clinical and Business Intelligence

CDS: Clinical Decision Support

2.



EHR: Electronic Health Record

3.



ePHI: Electronic Protected Health Information

ETL: Extract, Transform, and Load

4.



IoT: Internet of Things

MIoT: Medical Internet of Things

5.



PHI: Protected Health Information

Healthcare Data and Business Intelligence



Why Healthcare Data Matter

- **Healthcare organizations produce large amounts of data every day:**
 - **Data describe patients, services, costs, staff, and outcomes.**
 - **Leaders need these data to understand organizational performance.**
 - **Poor data can produce poor decisions.**
 - **Good data help leaders find problems and opportunities.**

What Is Business Intelligence?

- **Business Intelligence (BI) means using processes and technology to:**
 1. Turn raw data into useful information.
 2. Help users understand what is happening.
 3. Identify problems, patterns, and opportunities.
 4. Support better organizational decisions.
 5. Improve healthcare performance.

From Data to Action

- **Data:** individual facts, such as waiting times or test results.
- **Information:** organized data that have meaning.
- **Intelligence:** understanding what the information shows.
- **Decision:** selecting the most suitable action.
- **Action:** using the decision to improve performance.

Why Business Intelligence Is Important

- **Healthcare organizations are large and complex:**
 - **Leaders cannot depend only on personal observation.**
 - **BI shows how services and departments are performing.**
 - **It helps identify issues that require attention.**
 - **Without reliable BI, leaders may be “flying blind.”**

Main Elements of Business Intelligence

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➤ **A basic BI system includes:**

1. **Data collection**
2. **Data governance**
3. **A data warehouse**
4. **Reports and dashboards**
5. **Analytics and benchmarking**

➤ **These elements depend on one another.**

1. Data Collection

- **Data collection is the foundation of BI:**
 - **Data may describe patients, clinicians, costs, charges, or time.**
 - **Some important facts may not yet be collected electronically.**
 - **Organizations must know what data they already collect.**
 - **They must also identify what additional data are needed.**

Data Quality and Data Governance



What Is Data Quality?

- **Data quality means that data are suitable for their intended use.**
- **High-quality data should be:**
 - **Accurate:** they correctly represent what happened.
 - **Complete:** required information is not missing.
 - **Consistent:** the same rules and definitions are used.
 - **Timely:** data are available when needed.
 - **Accessible:** authorized users can obtain and understand them.

Why Poor-Quality Data Are Dangerous

- **Incorrect data can produce incorrect reports:**
 - **Missing data can hide important problems.**
 - **Different definitions can create unfair comparisons.**
 - **Old data may not describe the current situation.**
 - **A polished dashboard cannot correct unreliable source data.**

A Simple Data-Quality Example

- A patient's pain level could be entered as:
 - "Slight"
 - "Moderate"
 - "Bad"
 - "Very bad"
- These words may mean different things to different people. A defined 1–10 pain scale produces data that are easier to compare and analyze.

2. What Is Data Governance?

- **Data governance is the system of rules and responsibilities used to manage data.**
- **Data governance determines:**
 - Who may take action with data.
 - What actions are permitted.
 - When those actions may occur.
 - Which methods must be followed.
 - Who is responsible for the results.

Questions Answered by Data Governance

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➤ What does each data item mean?

- Who is responsible for entering and checking it?
- Who may view, change, share, or analyze it?
- How long should it be stored?
- How will errors and disagreements be corrected?

Governance Supports Trust

- **Data governance should ensure that:**
- Important data are collected consistently.
 - Staff use agreed definitions.
 - Data quality is checked regularly.
 - Data use follows approved rules.
 - Reports can be trusted by their users.

From Data Warehouses to Analytics



3. The Data Warehouse

- **Operational systems are designed mainly for daily work:**
 - They may not be designed for large reports or analysis.
 - A data warehouse stores data for reporting and BI.
 - Data from different systems can be combined there.
 - Data can then be checked and standardized.

Extract, Transform, and Load

- **Extract, Transform, and Load (ETL) is used to move data into a warehouse:**
 1. **Extract:** collect data from source systems.
 2. **Transform:** clean and standardize the data.
 3. **Load:** place the prepared data in the warehouse.
- **The process should preserve meaning and quality.**
- **Errors during ETL can affect every later report.**

4. Healthcare Reports & Dashboards

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- **Reports organize data into a readable format:**
 - They may contain tables, summaries, or graphs.
 - A summary report shows the overall situation.
 - A detailed report helps users investigate individual cases.
 - Reports are useful only when their source data are reliable.

4. Healthcare Reports & Dashboards

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- **A dashboard gives a quick view of important measures:**
 - **Colors may show whether results are on or off target.**
 - **Targets and budgets give numbers proper context.**
 - **A dashboard identifies where attention is needed.**
 - **It does not usually explain why the problem occurred.**

5. Analytics and Benchmarking

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- **Analytics means examining data to understand what they show.**
- **Analytics can help users:**
 1. Investigate why performance changed.
 2. Identify positive and negative trends.
 3. Find possible causes of a problem.
 4. Discover opportunities for improvement.
 5. Support an intervention or organizational action.

5. Analytics and Benchmarking

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- **Benchmarking means comparing performance with an external target or another organization:**
- **Everyone must use the same definitions.**
 - **Everyone must use the same counting rules.**
 - **Differences in definitions can make comparisons misleading.**
 - **Valid benchmarks help organizations set realistic targets.**
 - **Invalid comparisons may be useless or dangerous.**

Responsible Use of Healthcare Data



Responsible Secondary Use of Data

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- **Secondary use means using data for a purpose beyond the patient's immediate care:**
- **Examples include:**
 - **Measuring quality and organizational performance.**
 - **Planning services and allocating resources.**
 - **Studying trends across groups of patients.**
 - **Supporting approved research or improvement work.**
 - **Combining clinical and business data for management decisions.**
- **Secondary use still requires privacy, clear rules, and responsible oversight.**

Clinical and Business Data Together

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- Clinical systems focus mainly on individual patient care.
- Business systems focus on operations and financial performance.
- Combining both types gives leaders a fuller picture.
- The combined data can connect quality, outcomes, efficiency, and cost.
- Their use must follow clear governance rules.

More Data Do Not Always Mean Better Information

- **Healthcare produces very large and complex data sets:**
 - **Some data are structured; other data are free text or images.**
 - **Large volumes make manual review difficult.**
 - **Poor-quality data remain poor even when the volume is large.**
 - **The goal is useful information—not simply more data.**

Privacy, Confidentiality, and Patient Autonomy



Why Health Information Is Sensitive

➤ Health information may reveal:

- Diagnoses and treatments
- Medicines and laboratory results
- Mental or behavioral health information
- Personal and financial information
- Details that could cause harm if improperly disclosed
- Healthcare data are valuable to both legitimate users and criminals.

Privacy and Confidentiality

- **Privacy is a person's right to control personal information.**
- **Confidentiality is the duty to protect information entrusted to us.**
 - **Health data may include medical, personal, and financial details.**
 - **Access should be limited to legitimate purposes.**
 - **Greater electronic access creates both benefits and risks.**

Privacy Is a Moral Responsibility

- **Healthcare professionals handle highly personal information:**
 - They should protect other people's information as carefully as their own.
 - Ethical responsibility existed before electronic systems and privacy laws.
 - Legal compliance is the minimum expected behavior.
 - Respect for people should guide every use of their data.

Protected Health Information

- Protected Health Information (PHI) is identifiable information about a person's health or healthcare.
- Electronic Protected Health Information (ePHI) is PHI stored or transmitted electronically.
- **It should be:**
 - Used only for an appropriate purpose.
 - Available only to authorized users.
 - Protected against improper change or disclosure.

Patient Rights and Autonomy

- **Autonomy means respecting a person's right to make informed choices.**
- **Patients should have appropriate rights to:**
 - Examine their health information.
 - Obtain a copy of their records.
 - Request corrections to incorrect information.
 - Understand how their information may be used.
 - Give authorization when authorization is required.

Appropriate Access to Data

- **Access should match the person's job and responsibilities:**
 - **Not every employee needs access to every record.**
 - **Different roles may need different levels of information.**
 - **Access should be recorded and reviewable.**
 - **Excessive access increases the risk of misuse.**

Bias, Fairness, Accuracy, and Human Oversight



Bias in Data and Algorithms

- **Bias is a systematic unfair influence on data or decisions.**
- **Bias may occur when:**
 - **The data do not represent the whole population.**
 - **Some groups are missing or underrepresented.**
 - **Existing inequalities are present in historical data.**
 - **Different groups receive different measurements.**
 - **A system is used in a population unlike its training population.**

Bias Can Increase Health Inequality

- **“An algorithm learns patterns from its data”**
 - **Biased data can produce biased recommendations.**
 - **Using the system widely may spread the unfairness.**
 - **Large data volume does not automatically remove bias.**
 - **Results should be checked across different patient groups.**

Accuracy, Access, and Human Oversight

- Better access is not enough if advice is inaccurate.
- High accuracy does not remove the need for human judgment.
- Technology should support healthcare professionals, not blindly replace them.
- Users should be able to question or override a system when necessary.
- Responsible use requires accuracy, fairness, transparency, and monitoring.

Wrap-Up

1. High-quality healthcare data must be accurate, complete, consistent, timely, and accessible.
2. Data governance defines how data are collected, managed, protected, shared, and used responsibly.
3. Data warehouses, ETL, reports, dashboards, and analytics transform raw data into useful intelligence.
4. Healthcare data must be used ethically while protecting privacy, confidentiality, and patient autonomy.
5. Analytics and AI require fairness, accuracy, transparency, continuous monitoring, and human oversight.



Thank You