National Committee on Vital and Health Statistics

Advising the Secretary of Health and Human Services
on health information policy since 1949.

NCVHS

A Stewardship Framework for the Use of Community Health Data

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TOOLKIT FOR COMMUNITIES USING HEALTH DATA

How to collect, use, protect, and share data responsibly

A Report from the
National Committee on Vital and Health Statistics

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
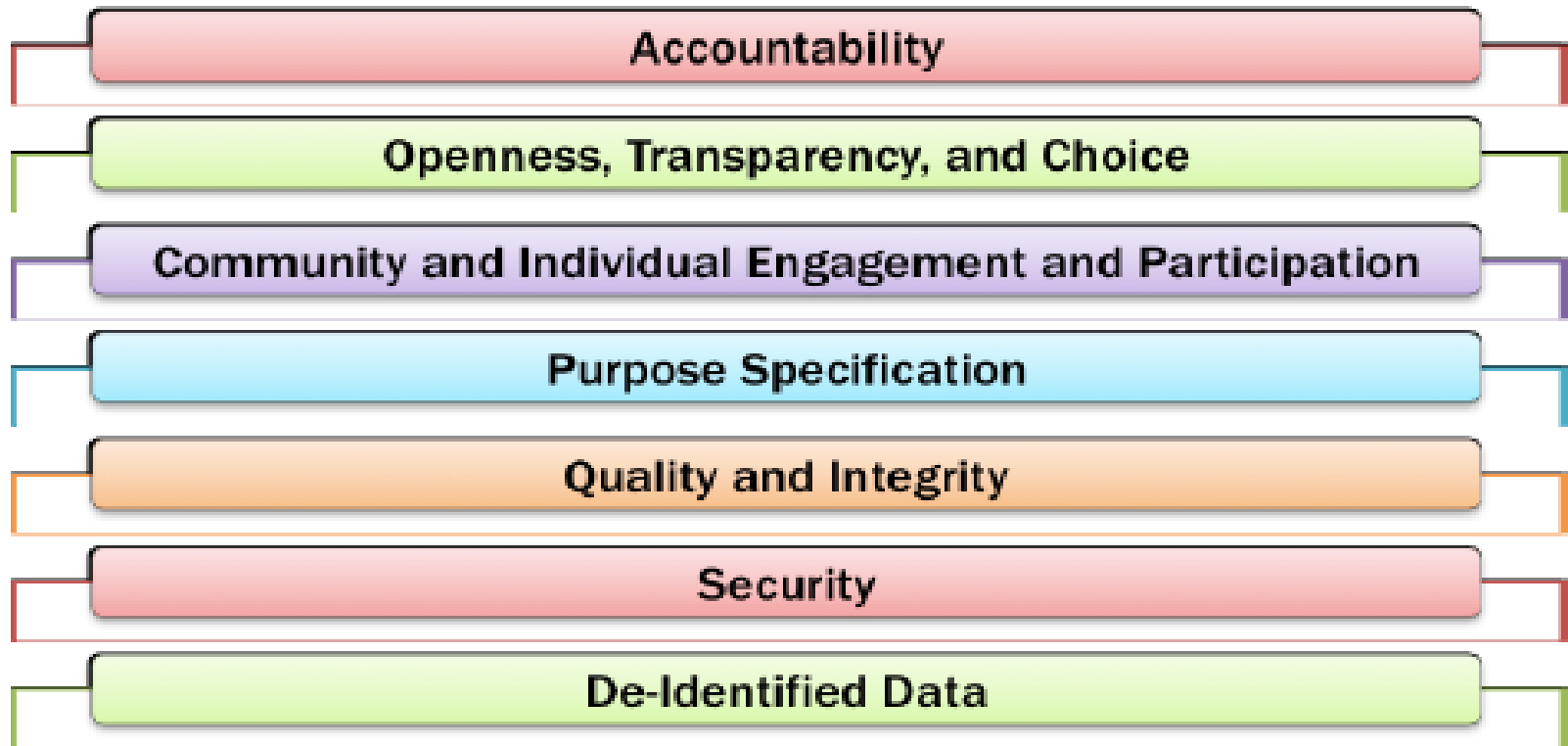National Center for Health Statistics

Why a Toolkit?

•Communities asked for practical guidance.

•Illustrates principles in NCVHS's letter to the Secretary on *Stewardship Framework for the Use of Community Health Data* (Dec 5, 2012)

•*Stewardship Framework* principles and their application defined, explained and illustrated.

•Applicable laws and regulations cited and explained.

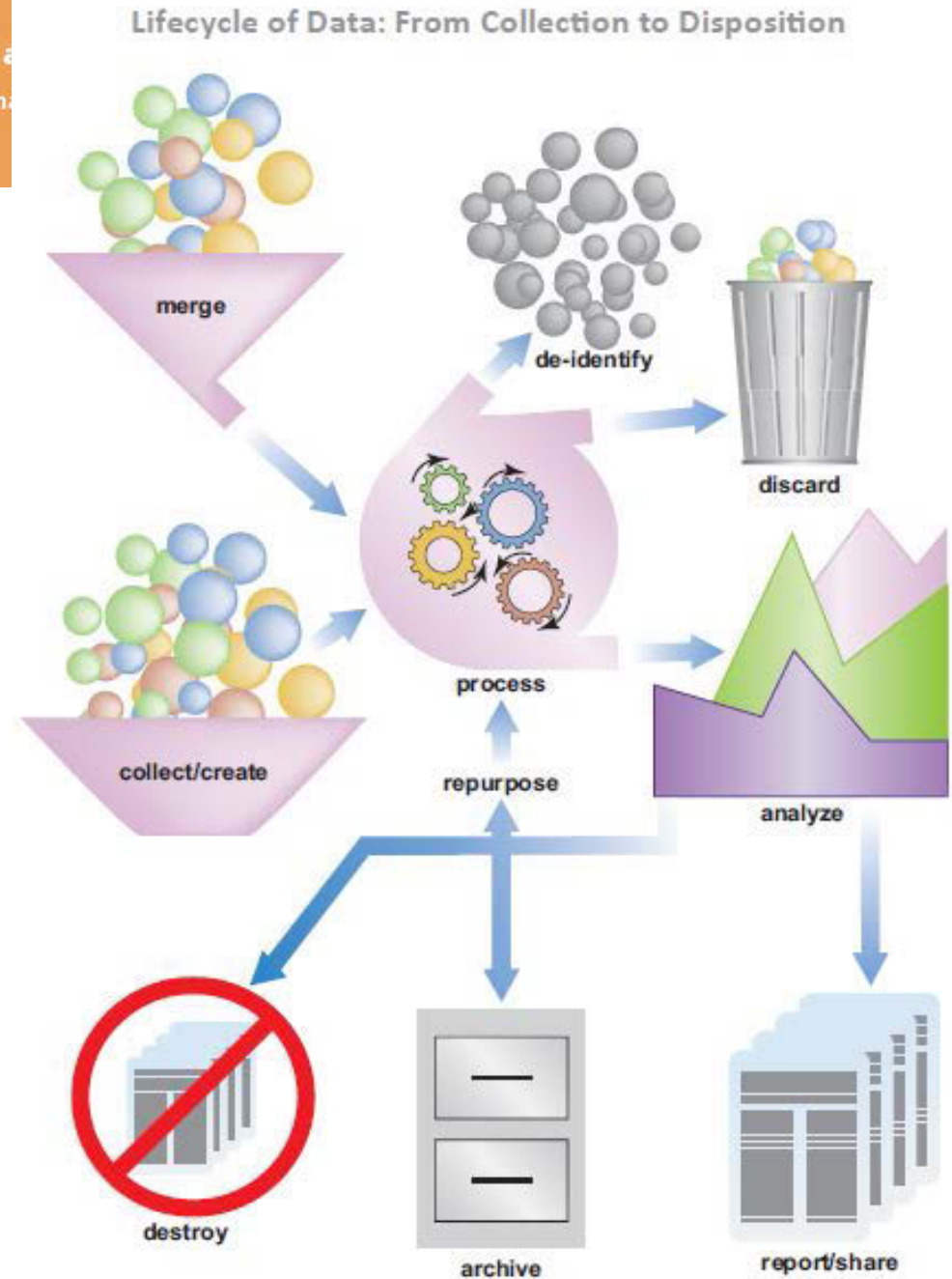•Practical tips, checklists and cautions highlighted to avoid missteps and potential harm.

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7 Principles of Data Stewardship

Accountability

Openness, Transparency, and Choice

Community and Individual Engagement and Participation

Purpose Specification

Quality and Integrity

Security

De-Identified Data

http://www.ncvhs.hhs.gov/wp-content/uploads/2013/12/Toolkit-for-Communities.pdf p. 15

Data Lifecycle

- Effective stewardship extends to all phases of lifecycle
- Community health data can be original data gathered for the purpose or repurposed data
- Use of repurposed data is expanding, driven by technology

Lifecycle of Data: From Collection to Disposition

merge · de-identify · discard · collect/create · process · repurpose · analyze · destroy · archive · report/share

http://www.ncvhs.hhs.gov/wp-content/uploads/2013/12/Toolkit-for-Communities.pdf p. 11

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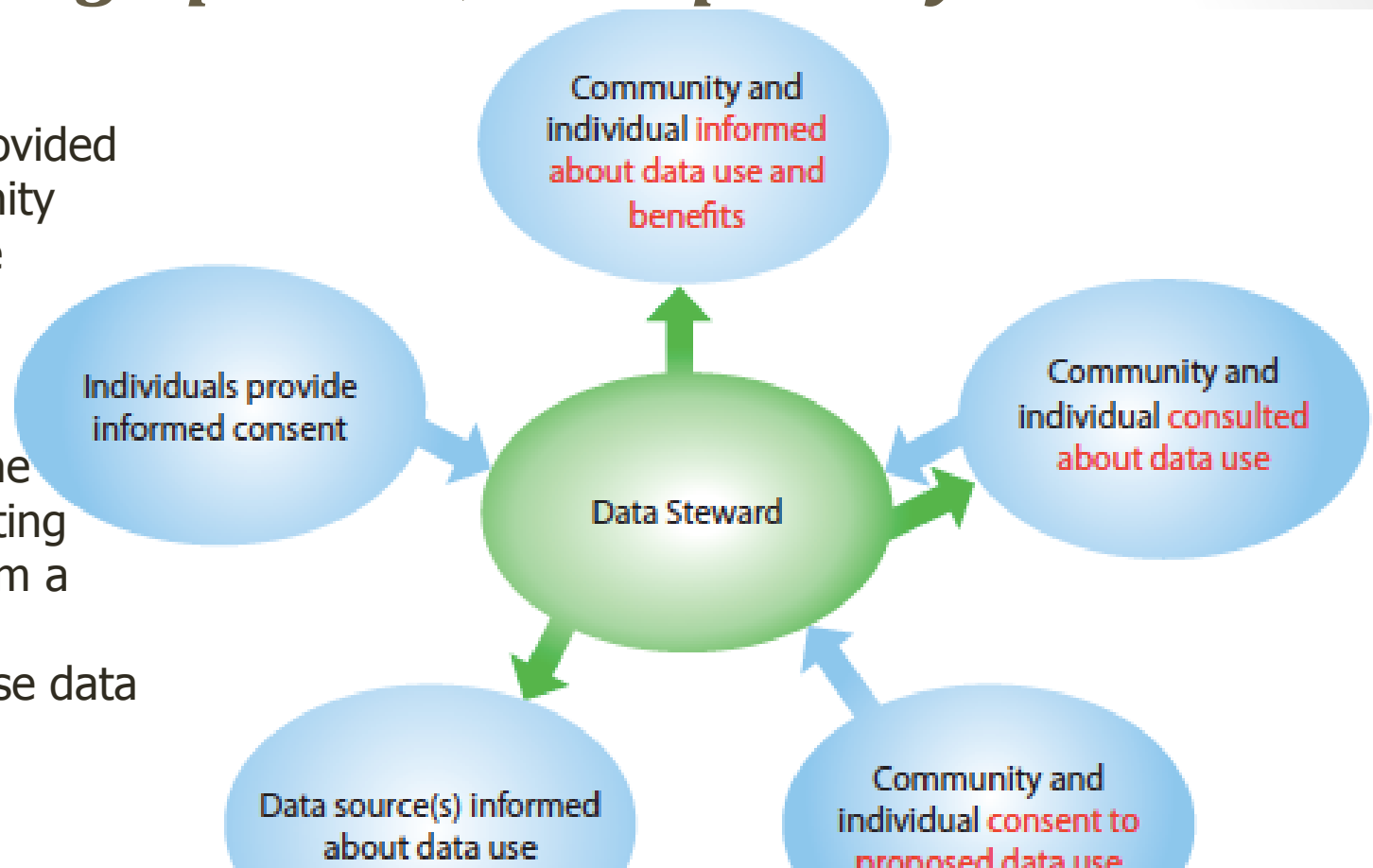on health information policy since 1949.

Accountability

- Accountability may lie with an individual or entity.

- Different people may be accountable for different phases of the data lifecycle or different stewardship elements.

- An accountable individual or entity should be named and held responsible for stewardship.

- Data use agreements (DUAs) are one way to establish accountability ground rules among data users.

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Advancing Openness, Transparency and Choice

Notice is information provided to the community about data use

Consent is the process of getting permission from a community or individual to use data

Community and individual informed about data use and benefits

Individuals provide informed consent

Data Steward

Community and individual consulted about data use

Data source(s) informed about data use

Community and individual consent to proposed data use

http://www.ncvhs.hhs.gov/wp-content/uploads/2013/12/Toolkit-for-Communities.pdf p. 18

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Community and Individual Engagement and Participation

- Evaluate opportunities for engaging communities and individuals at every step in the data lifecycle and across all elements of the stewardship framework.

- Be aware of the concerns of subgroups within communities whose interests may be different from those of the larger community.

- Consider the risk of stigmatization of communities or small groups and engage the community or individuals to determine an action plan for addressing the risk.

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Purpose Specification

- Engage the community in purpose specification.

- Address and align goals of collaborating entities regarding goals, funding, use limitations.

- Be aware that data may later be repurposed, design collection accordingly.

- When using repurposed data, consider the need for additional notice or consent.