

# Privacy and Confidentiality

Holly Taylor, PhD, MPH

*Department of Bioethics*

*NIH Clinical Center*

# Disclaimer

The views expressed in this talk are my own.  
They do not represent the position or policy  
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# Overview

- Privacy & Confidentiality: Definitions
- Why Privacy & Confidentiality Matter
  - Respect
  - Risks of Harm
- Respecting Privacy in Research
- Ensuring Confidentiality

# Privacy and Confidentiality

- Privacy
  - Limiting unauthorized, active or passive disclosure of personal, sensitive information
- Confidentiality
  - Protection of private information shared with investigator

# Privacy and Confidentiality

Why are we concerned, morally speaking?

- *Respect for persons*
  - Respect desires of individuals to keep certain information private and their autonomy to choose who should have access to private information
  - Keep promises that private information shared in the context of research will be kept confidential

# Privacy and Confidentiality

Why are we concerned, morally speaking?

- *Risk of harm*

- The desire to keep certain information private can stem from a fear or real threat of harm, should that information become more widely known.
- Obligation to respect privacy and avoid breaches of confidentiality increases as sensitivity of information increases (e.g. drug use, HIV status, etc..)

# Risk of Harm

- Types of Individual Harm
  - Physical
  - Psychological
  - Social
    - Risks to reputation/stigma
      - Breaches of confidentiality
  - Economic

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# Risk of Harm

- Types of Community Harm
  - Social
    - Risks to Reputation/Stigma
  - Economic
  - Exploitation
    - Harms to individuals by virtue of group membership
    - Harms to structured groups with ongoing existence/interests

# Risk of Harm

- Types of Community Harm
  - Research examining the prevalence of an “alcoholism” gene among different racial/ethnic groups
  - Prevalence studies showing higher rates of mental illness in certain subgroups of population

# Respecting Privacy

- Privacy
  - How will subjects be recruited?
    - Personal invitation from Investigator
    - Physician referral
    - Chart review
      - Email/Letter from physician
      - Email/Letter from investigator

# Respecting Privacy

- Privacy
  - Where will research be conducted?
    - Private home
      - In-person
      - phone
    - Private office
    - Local clinic

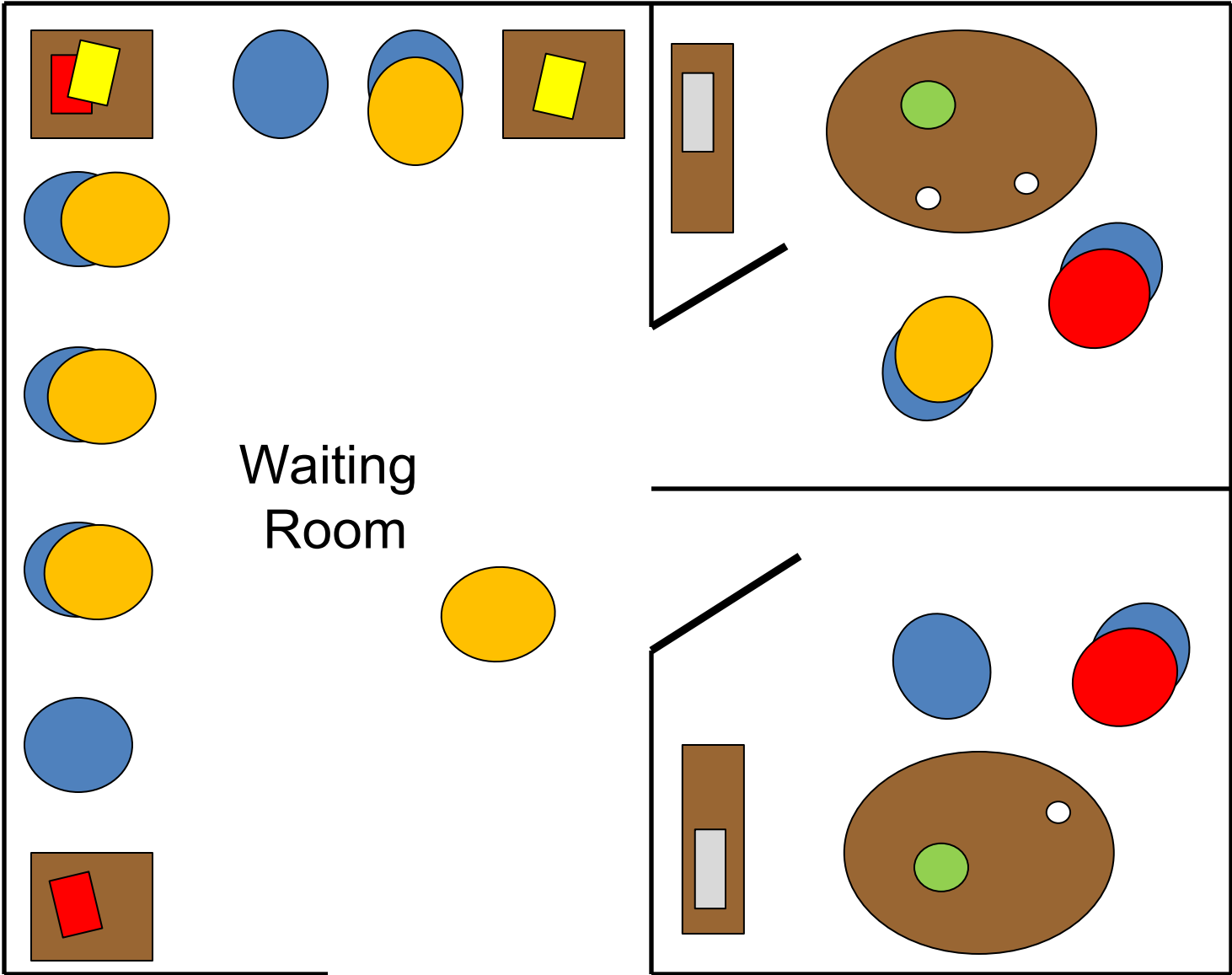


# Respecting Privacy

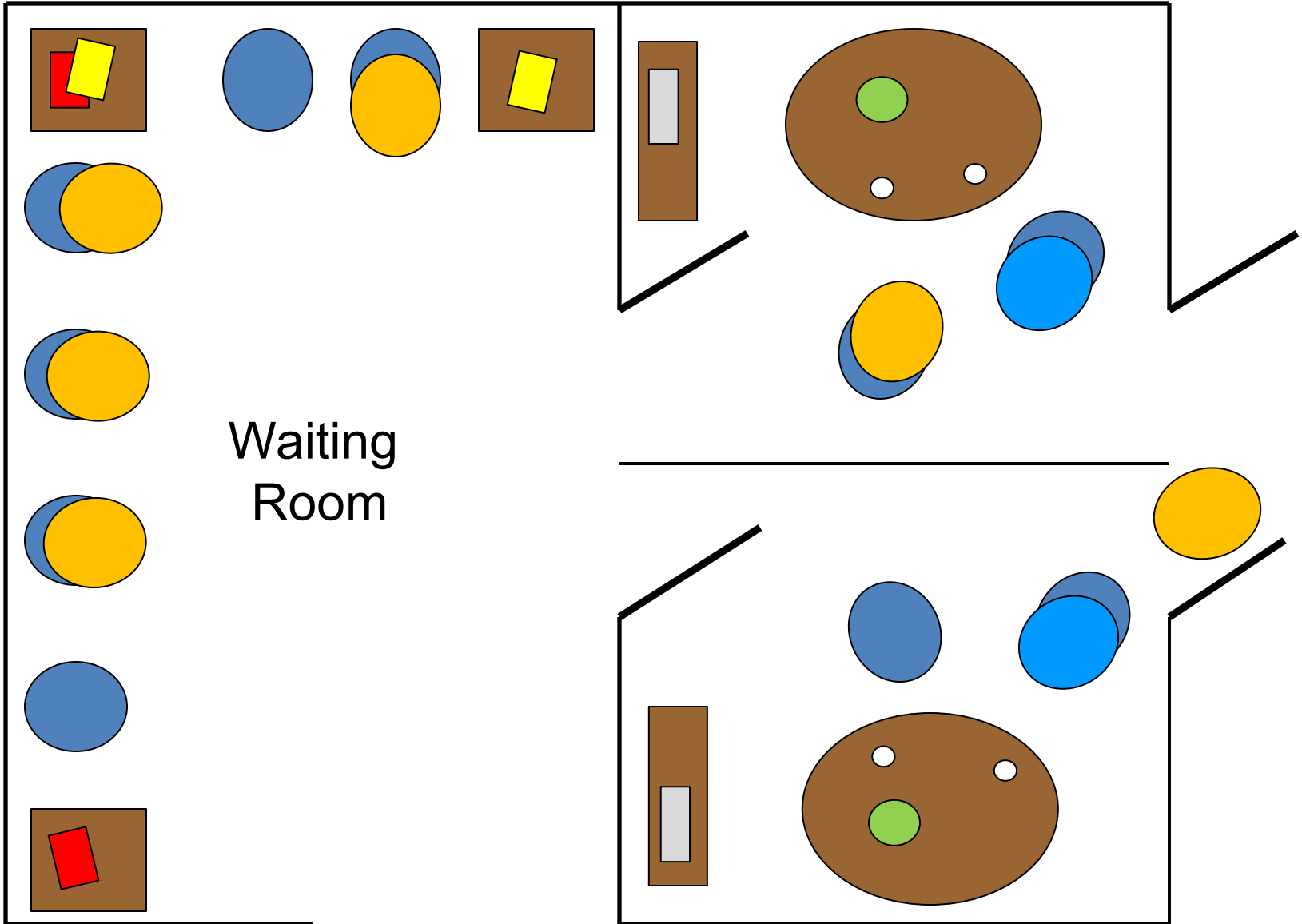
- Privacy
  - Logistics of interview
    - How long will the interview last?
    - Who will conduct the interview?
    - Will the interview be tape/video recorded?

# Respecting Privacy

- Privacy
  - Does participation alone lead to stigma?





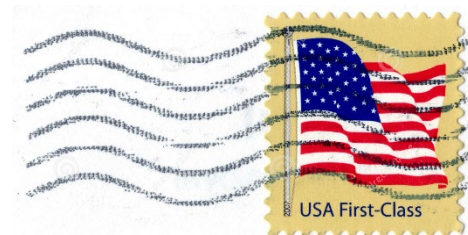


Waiting  
Room

# Privacy

- Privacy
  - For longitudinal studies, how will subjects be contacted for future visits
    - Letter/Email
    - Phone
    - Visit to home

HIV Vaccine  
Study



Holly Taylor  
1234 Calvert St.  
Baltimore, MD 21202

# Confidentiality

- Confidentiality
  - Protection of private information shared with investigator

# Confidentiality

- Confidentiality
  - Is there a need to collect identifiable information?
  - Does signing the consent form and/or the consent form itself create an opportunity for a breach?

# Confidentiality

- Confidentiality
  - Appropriate data management requires standard operating procedures/infrastructure
    - Data transport
    - Locking file cabinets/office
    - Computer that can be pass-word protected
    - Encryption of data

# Confidentiality

- Procedures to Limit Breach of Confidentiality
  - Research staff training
  - Data management
    - Research materials should be labeled with a unique identifier rather than names
    - Keep list that links name and unique identifier separate and both of these separate from consent form

# Privacy and Confidentiality

- Other considerations
  - Cultural norms differ
  - Partner notification
  - Publication of results may disclose sensitive information about an entire community



# Privacy and Confidentiality

- Collect identifiable information only if you have a good reason to do so!