Research Gaps and Traps

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NASEM Workshop on Data Needs in the Wake of the Dobbs Decision

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Treatments During Pregnancy Impacted

- Management of incomplete spontaneous abortions (miscarriages)
  - Treatment of hemorrhage
  - Treatment of infection
  - Treatment in case of water breaking/risk of infection
- Management of ectopic pregnancies
- Management of pre-eclampsia
- Management of fetal anomalies
- Treatment for cancer
- Treatment for other urgent conditions (e.g. organ transplants, addiction, mental illness)

Quality and Access to Care Impacted

- No longer possible to provide high quality care in many states
  - Women's health care deserts
  - Provider decision-making curtailed so best treatment not possible

- Patients sicker since needed care must be postponed or not provided at all

- Risks to future fertility increase with denial of appropriate care

- Hospitals obscuring information about their abortion services

Beyond Pregnancy: Most of women's lives are spent not pregnant

- Women and girls of "reproductive age" are being denied access to treatments where the treatment could cause an abortion
- Reproductive age is being arbitrarily defined (e.g. below age 10, above 50)
- Some types of care impacted:
  - Cancer treatment
  - Dermatology treatments
  - Lupus treatment
  - Organ transplants
  - Some cardiac conditions
  - Mental illness treatment
  - Addiction treatment

Data Needs

- We need all types of data, from randomized control trials to health statistics to surveys to qualitative methods to deep involvement from communities in the design, conduct and interpretation of research.
- We also need to understand policy perspectives, clinical enablers and limitations, access to care, and the impact of health care provider attitudes and practices towards individuals and members of ethnic and socio-economic groups.
- Not just **what**, but also **why**: How to improve?
- How do place our data in the context of the social determinants of health?

Access to Health Care Parameters

- Financial: Insurance, transportation, co-pays, medication
- Transportation availability/distance/time
- Ability to miss work, school, etc.
- Child care
- Convenient hours of services
- Service experience: Respect, real/perceived needs met?
- Language/clear communication

A Few Problems with Data Quality

- Accurate recording of clinical encounters, records
- Socially desired responses rather than honest responses
- Meanings of questions can be interpreted different ways
- Distrust of research/research/clinician/registrar
- Cannot probe in-depth
- Cannot allow for the unexpected
- Important contextual factors may be neglected

Data Needs

- Patterns and interrelationships need to be understood
- Perspectives of multiple disciplines needed
- Community voices need to be present and respected
- Risks to women of providing data need to be understood
- Multiple levels of analysis and understanding needed: Individual, family, community, region, state, national.
- Multiple perspectives need to be studied: Health care professional, policy maker, individual, family, community, etc.

More Missing Data

- Concerns that data will be impounded is influencing accurate data recording
- Some states will no longer collect data on pregnancy outcomes in order to avoid recording adverse outcomes
- Some states are blocking access to prenatal testing for fetal anomalies
- Aps to track menstrual cycles pose a risk to women in states where the data may be used against them

Thank you

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