

## BLOOM Advisory Group Meeting #1

*March 14th 2025*

**Attendance:** Jeffrey Kahn, Alta Charo, Anna Mastroianni, Debra Mathews, Ruth Faden, Leslie Meltzer Henry, Geoff Lomax, Joanne Rosen, Kim Mutcherson, Jerrine Morris, Judith Darr, Robert Cook-Deegan, Kimberly Mutcherson, Katie Cameron, Ripple Sato, Katherine Cheung

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### **Welcome & Zoom Introductions**

The members of the Core Project Team and Advisory Group introduced themselves to the group (biographies can also be found on the [BLOOM Intranet](#)).

### **BLOOM Project Overview & Discussion**

The Core Project Team provided a brief overview of the project, and its background (can also be found on the BLOOM Intranet).

The project will involve 5 meetings over the course of 2025, with one in-person meeting and four virtual meetings. The in-person meeting will take place May 7th 2025, in Washington D.C. at the Hopkins Bloomberg Center (555 Pennsylvania Avenue). Between meetings, work will be done over email.

- Please email Katherine Cheung ([kcheun20@jh.edu](mailto:kcheun20@jh.edu)) and Susan Snead ([ssnead2@jhu.edu](mailto:ssnead2@jhu.edu)) if you require travel support for the May 7th D.C. Meeting.
- A calendar invite will be sent to the Advisory Group for the May 7th meeting.

The proposed work products of the project are the model law components (which will be published, as well as made available on the Berman Institute website), a manuscript analyzing state trends, a process document (on the methodology of the project), and potentially briefings for state legislative staff.

An Intranet has been set up for the project ([link](#)): this is a private site, and cannot be accessed without the link.

Meeting minutes and a recording of the meeting will be shared, for internal use only.

Project asks:

- Please send any relevant materials to Katherine to share with the group. For example,
  - Surrogacy legislative debates in the 1980s
  - Model legislative efforts that you are aware of
  - International legislative efforts
  - Contacts for legal counsel at major stakeholder groups
- There is also a need for a Research Assistant (RA) with expertise in legislative drafting.
  - If you are aware of someone teaching a legislative drafting course, and may have a student, please let us know.

As of now, the Core Project Team and RAs have been working on:

- Gathering existing state law (statutes, regulations & cases) on embryo disposition & management
- Gathering organizational position statements and existing clinic embryo disposition & management policies
- Gathering bioethics literature on embryo disposition & management (e.g., donor and clinician attitudes, ELSI, religious perspectives)

## Group Discussion

The following questions were posed to the group for discussion:

- What should be the scope of the project?
- What practical needs and challenges might there be within the clinic that the model legislation should address?
- What are the legal and policy issues that model legislation should address?
- What are the key areas that should be harmonized across the United States?
- Are all important stakeholders represented?
- What topics should we put on hold?
- What resources should we know about?

### Scope of the project:

#### *Items out of scope:*

- The group discussed not including quality assurance or clinical issues around storage within the scope of the project.
- The group discussed model federal legislation as out of scope for the project.
  - The project will focus on state law as a way to instantiate bioethics into policy, with work potentially to be done at the federal level in the future.
- The group discussed staying away from interstate commerce.

#### *Items within scope:*

- The group discussed the inclusion of gametes.
  - It is harder to research state law on gamete ownership than embryo ownership.
  - The group raised the question of whether clinics have seen disputes regarding gametes.
    - Clinicians responded that disputes seen have mainly been posthumous.
  - Clinics discuss all possibilities, but nudge patients towards freezing oocytes, as it gives the patient complete dispositional control.
  - Is the loss rate of oocytes after freeze/thaw cycle roughly equivalent to that of embryos?
    - Clinicians responded that overall, the answer is yes. However, attrition occurs at each stage of the IVF process (e.g. not all eggs of the ones retrieved will be mature). Making and freezing embryos sometimes makes more sense as it gives you more information about what you have in inventory. We can be more confident about the reproductive potential of an embryo.
    - There are also concerns about transferring gametes that have been stored at other labs, and how they will do at the new lab. Some of these concerns don't apply for embryos that are stored elsewhere then transferred.
  - Gametes may be involved in cases where a donor has been commissioned, makes a directed donation, makes frozen oocytes, then changes her mind about that couple.
  - A case involving gametes: <https://www.scientificamerican.com/article/consumer-dna-tests-negate-sperm-bank-donor-anonymity/>
- The group discussed how recontact is handled (e.g. where people donated excess embryos for research but it turned out they were never used and now there is a question of whether they should just be discarded)
  - From CIRM: We have advised researchers accepting embryo donations to disclose that the embryo may be destroyed and not utilized in research. Last I heard, some institutions keep embryos and not destroy them due to lack of consent.
  - This should always be clarified up-front.

- The group discussed how the connection to abortion/personhood cannot be avoided.
  - Related to abortion, one concern is overregulation that usurps or interrupts the physician/patient relationship (i.e., biased informed consent, waiting periods, procedures that can/can't be performed, etc.)

### Project Approach

The group discussed identifying shared assumptions that are guiding the project's work, such as:

- A commitment to facilitating IVF (in ways that are ethical and accessible and instantiate best medical practice standards)
- Respect for the autonomy of the parents/donors
  - For example, probing the parent/donor autonomy commitment, what about the option of embryo "destruction"? Is this a foundational assumption or is this an a, b, c kind of thing?
  - What do we know about the intersection of those in the public and political positions/state laws that support access to IVF but oppose discarding or research uses of embryos on personhood grounds? Is this an a, b, c issue or a nonstarter?
- Creating something that allows for adaptation.
- Not ignoring contemporaneous consent

Core Project Team to potentially bring a draft of shared assumptions to the next meeting.

The group discussed taking a life cycle perspective on the project. For example, including prenuptial agreements, considering inheritance patterns, wills.

The group discussed following the model of the Uniform Parentage Act (e.g. creating Options A, B and C).

- The group might consider writing some basic foundational principles, and then providing different options.
- It doesn't need to explicitly recognize the abortion issue, but it should acknowledge that different states have different stances.

The group discussed the risk of giving people/states ideas you don't want them to have.

- The project potentially can provide better tools for states to make laws that are effective, but it cannot control what states do with their laws.

### What practical needs and challenges might there be within the clinic that the model legislation should address?

The group discussed the issue of the transportation of embryos (e.g. from one clinic to another, from one state to another).

- Clinicians added that the transfer of cryopreserved embryos happens all the time, for logistical reasons (e.g. patient moves). They have not yet encountered couples who moved embryos anticipating legal battles. Embryos cross state lines all the time.
- Some patients do move states, but want their embryos to remain in Maryland.
  - There is a heightened awareness since the Alabama decision that the embryos are "safe" in Maryland.
- The group also discussed cases where there are aspirations of transferring an embryo from a state that has some sort of restriction to California.
  - From CIRM: Institutions would say no because of the restrictive law, but this does seem to diminish the rights and autonomy of the individual who wants to make the donation.
  - Usually as the receiving institution does not want to violate the law in another state.
- The question was raised as to whether it matters if couples transfer the embryos themselves, or whether it's through a courier.

- Clinicians responded that individuals often choose to use a courier, as they don't want to be responsible for liquid nitrogen levels. There are fertility specialized couriers.
- The question was raised as to whether individuals might need to prove that they are living in that state to ship?
  - Some people go to clinics out of state for discounts.
- Could a state regulate the couriers, and say that certain things cannot be transported?
- How would a state know what the intention for transporting the embryo is?
- There are reports in the press from Louisiana that the clinics had the experience of transferring embryos to states where disposal was permitted (e.g. see [this article](#))
- Choice of laws: whose state laws control when there are multiple states involved? How much do we want to get into this issue?
- Clinicians also raised that the issue of state transportation is one that should be addressed, as patients are often very motivated and very well-read. If patients think that they are in a position where embryos might be safer elsewhere, they will move the embryos.

The group discussed how patients are often focused on getting pregnant, and that they're often not thinking about what happens in the future.

- Many patients who are receiving IVF have wanted to conceive for a long time.
- Human reproduction is often very inefficient, and a large number of eggs are needed. Excess embryos are inevitable.
  - There are worries from the couple as well about not having enough eggs.
- There is little time for clinicians to focus on the issue of excess embryos.
  - Having something to provide to patients on this issue would be helpful.
- Might also be helpful to know how many embryos are being frozen with dispositional direction - do we want to know how many? Do we want to highlight this number?
- Patients are often unsure about how to think about embryo disposition.
- Storage is a significant issue: what do clinics do with remaining embryos?

The group discussed how embryo disposition is currently handled in clinics.

- The clinicians discussed how embryo disposition decision-making and consent are a required pre-step prior to undergoing IVF.
- SART has a model form that many clinics adapt and use.
- However, there isn't consensus on what to do if individuals are no longer aligned on preferences.

#### Are all important stakeholders represented?

- The group discussed the potential inclusion of a patient advocate in the project, such as having a representative from the infertility community, especially as clinicians may not experience the emotional impact of the IVF process.
  - Jerrine has some contacts for advocates on embryo donation.
- The group also spoke about the importance of being sensitive to the fact that there are donors and other progenitors that may be neglected in the conversation. There are also interest groups of children who have been created from donors.

#### What resources/materials should we know about?

- The group recommended a few resources:
  - [ABA's model act governing assisted reproductive technologies](#) (2008)
    - There is a section on the disposition of unclaimed/abandoned embryos
  - [Uniform Parentage Act](#)
    - Includes some language on disposition
  - ASRM Ethics Committee opinion
    - Has advice on unclaimed embryos and disposition
  - Project 2025

- According to NARAL, page 461 of Project 2025 says “Refuse to protect IVF and other fertility treatments Suggests that in-vitro fertilization become "fully obsolete and ethically unthinkable.” (p.461)”
- “In addition, the Administration should reconvene a new National Council on Bioethics (NCB) to discuss new and emerging areas of ethical concern, to assess whether the ends justify the means when it comes to the promise of therapies and cures, and to establish what limiting principles should guide research and health policy. Because the male–female dyad is essential to human nature and because every child has a right to a mother and father, three-parent embryo creation and human cloning research should be banned. A new NCB should convene leading experts to examine these issues and provide policy recommendations for the new frontier of bioethical questions that our country will have to address in the coming years. Finally, HHS should create and promote a research agenda that supports pro-life policies and explores the harms, both mental and physical, that abortion has wrought on women and girls.”
- Committee on Science, Technology and Law at NASOM was looking at IVF and embryo disposition last spring
  - Look into finding out what they’ve done.