

Certificate in Surrogacy and Reproductive Technologies Law

Genetic Testing, Disclosure, and Legal Implications

Ableism – concept: discrimination based on perceived disability, often arising when genetic test results suggest a higher risk of future health issues. Related terms: discrimination, disability rights. Explanation: In surrogacy contexts, ableism can affect how intended parents view embryos with potential genetic conditions, influencing selection or disposal decisions. Example: An intended couple rejects an embryo flagged for a treatable metabolic disorder, citing “quality of life” concerns. Challenges: Balancing respect for autonomy with ethical obligations to avoid prejudicial attitudes toward genetic diversity.

Accredited Laboratory – concept: a facility that meets national or international standards for performing genetic testing. Related terms: CLIA, ISO 15189. Explanation: Surrogacy agencies must ensure that DNA profiling, carrier screening, and pre-implantation genetic testing (PGT) are conducted in accredited labs to guarantee accuracy and legal admissibility. Example: A clinic partners with a CLIA-certified lab for PGT-A (allele) to detect single-gene disorders. Challenges: Verifying continuous compliance, managing costs, and addressing cross-border testing where accreditation standards differ.

Adverse Selection – concept: the practice of choosing embryos or gametes based on genetic information that may lead to ethical or legal concerns. Related terms: embryo selection, eugenics. Explanation: Intended parents may prefer embryos without known disease-risk alleles, potentially raising claims of discrimination against embryos with disabilities. Example: Selecting only embryos free of cystic fibrosis mutations while discarding others. Challenges: Aligning selection criteria with national anti-discrimination statutes and professional guidelines.

Amended Consent – concept: a revised informed consent document reflecting new information or changes in the testing protocol. Related terms: informed consent, addendum. Explanation: When additional genetic panels are introduced after initial gamete donation, parties must receive an amended consent outlining new risks, benefits, and disclosure options. Example: Adding a pharmacogenomics panel to the original consent for a surrogate’s egg donation. Challenges: Ensuring timely delivery, avoiding consent fatigue, and documenting the amendment for evidentiary purposes.

Anonymous Donor – concept: a gamete donor whose identity is not disclosed to the recipient or child. Related terms: donor anonymity, open-identity donation. Explanation: Many jurisdictions permit anonymous donation, but genetic testing can inadvertently reveal donor identities through familial matching databases, creating legal tension over privacy. Example: A child conceived via anonymous sperm discovers a half-sibling through a direct-to-consumer DNA service. Challenges: Reconciling donor confidentiality with a child’s right to know genetic origins under emerging “right-to-information” laws.

Assisted Reproductive Technology (ART) – concept: medical procedures that aid in achieving pregnancy, including IVF, ICSI, and surrogacy arrangements. Related terms: IVF, IUI, surrogacy. Explanation: Genetic testing is integral to many ART cycles, providing information on embryo viability, carrier status, and disease risk. Example: Using PGT-SR (structural rearrangements) to screen embryos for balanced translocations. Challenges: Navigating varying national regulations on permissible tests and the extent of required disclosure.

Beneficiary – concept: the intended parent(s) who will receive custody of the child born through surrogacy. Related terms: intended parents, legal parent. Explanation: Beneficiaries have a vested interest in genetic testing outcomes, influencing decisions on embryo transfer, disclosure to the surrogate, and future medical care. Example: Beneficiaries request comprehensive carrier screening to avoid passing recessive conditions to offspring. Challenges: Aligning beneficiaries' preferences with the surrogate's rights and statutory limits on selective disclosure.

Biological Parentage – concept: the genetic relationship between a child and the gamete providers (egg and sperm donors or the surrogate's own gametes). Related terms: genetic link, parentage determination. Explanation: DNA testing establishes parentage for legal documentation, immigration, and inheritance matters. Example: Post-birth DNA testing confirms that the surrogate's egg was not used, supporting intended parents' claim. Challenges: Disputes arise when test results contradict prior agreements, leading to custody or child-support litigation.

Carrier Screening – concept: genetic testing to identify individuals who carry a single copy of a recessive disease-causing allele. Related terms: recessive disorder, premarital screening. Explanation: In surrogacy, carrier screening of both gamete donors and intended parents helps avoid implantation of embryos at high risk for serious conditions. Example: Detecting that both intended parents are carriers of sickle-cell disease, prompting the use of donor gametes. Challenges: Managing false-positive results, cultural sensitivities, and ensuring that screening does not become a de-facto eligibility filter prohibited by anti-discrimination law.

Child Custody – concept: legal authority to make decisions concerning a child's upbringing, education, and health. Related terms: legal parentage, guardianship. Explanation: Genetic test results can influence custody disputes, especially when one party contests parental rights based on alleged misrepresentation of genetic risk. Example: A surrogate seeks custody after learning the intended parents concealed a high-risk genetic finding. Challenges: Courts must balance best-interest standards with contractual obligations and the weight of genetic evidence.

Clinical Validity – concept: the extent to which a genetic test accurately predicts a clinical condition. Related terms: test sensitivity, predictive value. Explanation: Courts scrutinize the clinical validity of tests used in surrogacy agreements when disputes arise over alleged misdiagnosis or misleading information. Example: A court dismisses a claim that a PGT-M (monogenic) test was faulty because the test's sensitivity exceeds 99%. Challenges: Rapid advances can outpace regulatory review, leading to disputes over "experimental"

versus “standard-of-care” status.

Confidentiality – concept: the duty to protect private information from unauthorized disclosure. Related terms: privacy, data protection. Explanation: Genetic data generated during surrogacy is highly sensitive; parties must negotiate confidentiality clauses covering storage, sharing, and future access. Example: A surrogacy contract stipulates that the surrogate’s DNA profile will be destroyed after birth. Challenges: Legal obligations to disclose certain findings (e.g., non-paternity) may conflict with confidentiality promises, especially under mandatory reporting statutes.

Consent – concept: voluntary agreement to undergo genetic testing after being fully informed of risks, benefits, and alternatives. Related terms: informed consent, autonomy. Explanation: Consent must be obtained from donors, intended parents, and surrogates, each with distinct informational needs. Example: A surrogate signs consent acknowledging she will receive limited disclosure about embryo genetic status. Challenges: Ensuring comprehension across language barriers, cultural differences, and varying literacy levels.

Counselling – concept: professional guidance provided before and after genetic testing to help individuals understand implications. Related terms: genetic counseling, psychosocial support. Explanation: Mandatory pre-test counselling reduces misinterpretation of results and supports informed decision-making in surrogacy. Example: A certified genetic counselor explains the difference between carrier status and disease manifestation to intended parents. Challenges: Limited availability of counselors with expertise in reproductive law, potential conflict of interest when counsellors are employed by the ART clinic.

DNA Profile – concept: a unique pattern of genetic markers used for identification and parentage testing. Related terms: STR analysis, forensic genetics. Explanation: DNA profiling is the cornerstone of legal parentage verification in surrogacy cases. Example: Short tandem repeat (STR) analysis confirms that the child’s DNA matches the intended father’s sample. Challenges: Contamination, mixed samples (e.g., maternal tissue in embryo biopsies), and interpretation of low-level mosaicism.

Direct-to-Consumer (DTC) Testing – concept: genetic testing services marketed directly to consumers without a medical intermediary. Related terms: consumer genomics, privacy. Explanation: DTC results can reveal unexpected familial relationships, undermining anonymity agreements in surrogacy. Example: A child uses a DTC kit and discovers a half-sibling from the same donor. Challenges: Regulating the admissibility of DTC results in court and reconciling them with confidentiality clauses.

Embryo Biopsy – concept: the removal of one or more cells from an embryo for genetic analysis. Related terms: trophectoderm biopsy, blastomere. Explanation: Biopsy is performed at the cleavage or blastocyst stage to enable PGT without compromising embryo viability. Example: Trophectoderm biopsy yields cells used for comprehensive chromosome screening (CCS). Challenges: Potential harm to embryo development, mosaicism interpretation, and legal disputes over whether the biopsy constitutes “manipulation” prohibited in some jurisdictions.

Embryo Disposition – concept: the decision regarding the fate of embryos not transferred, including donation, research, or destruction. Related terms: embryo donation, discard policy. Explanation: Legal frameworks often require explicit consent for each disposition option, and genetic findings can influence choices. Example: Embryos flagged for a severe genetic disorder are offered for research under a separate consent. Challenges: Balancing respect for donor intent, religious objections, and the potential value of embryos for future therapeutic use.

Embryo Selection – concept: choosing which embryo(s) to transfer based on genetic, morphological, or other criteria. Related terms: PGT, elective transfer. Explanation: Selection may prioritize embryos free of detectable pathogenic variants, raising ethical concerns about “designer babies.” Example: Selecting an embryo free of BRCA1 mutation despite the parents’ low penetrance risk. Challenges: Determining the legal threshold for permissible selection and avoiding discrimination claims.

Ethical Review Board (ERB) – concept: a committee that evaluates the ethical aspects of research or clinical protocols involving human subjects. Related terms: IRB, ethics committee. Explanation: Surrogacy clinics conducting experimental genetic tests must obtain ERB approval to ensure compliance with ethical standards. Example: An ERB reviews a protocol for whole-genome sequencing of embryos. Challenges: Divergent standards across jurisdictions and the need for rapid review given the time-sensitive nature of IVF cycles.

Expanded Carrier Screening (ECS) – concept: a broad panel testing for dozens to hundreds of recessive conditions simultaneously. Related terms: multiplex testing, panel testing. Explanation: ECS is increasingly offered to intended parents and donors to reduce the risk of recessive disease in offspring. Example: An ECS panel identifies carrier status for both cystic fibrosis and spinal muscular atrophy. Challenges: Interpreting variants of uncertain significance, cost coverage, and potential for information overload leading to decision paralysis.

Family Law – concept: the area of law governing marriage, parentage, custody, and related matters. Related terms: matrimonial law, child welfare. Explanation: Surrogacy agreements intersect with family law when determining legal parentage, especially after the birth of a genetically related child. Example: A jurisdiction requires a post-birth adoption decree for intended parents to become legal parents. Challenges: Harmonizing family-law statutes with international surrogacy arrangements and genetic evidence.

Genetic Counseling – concept: a communication process that helps individuals understand the medical, psychological, and familial implications of genetic information. Related terms: risk communication, counseling session. Explanation: In surrogacy, counselors address issues such as carrier status, disease risk, and the impact of disclosure on the surrogate-intended parent relationship. Example: A counselor explains autosomal recessive inheritance to a couple considering donor gametes. Challenges: Limited counselor availability, potential bias if employed by the ART provider, and ensuring culturally appropriate communication.

Genetic Discrimination – concept: adverse treatment of individuals based on genetic information. Related terms: GINA, insurance bias. Explanation: Intended parents may face discrimination from insurers if a genetic test reveals a high-risk allele in an embryo or donor. Example: An insurance company raises premiums after learning the embryo carries a BRCA2 mutation. Challenges: Enforcement of anti-discrimination statutes and the tension between risk assessment and privacy rights.

Genetic Information Nondiscrimination Act (GINA) – concept: U.S. federal law prohibiting discrimination based on genetic information in health insurance and employment. Related terms: statutory protection, HIPAA. Explanation: While GINA offers protections, it does not cover life, disability, or long-term care insurance, leaving gaps relevant to surrogacy participants. Example: A surrogate's health insurer denies coverage for a pre-existing condition uncovered by carrier screening. Challenges: Applying GINA's scope to cross-border surrogacy and interpreting "genetic information" in the context of embryo testing.

Genetic Privacy – concept: the right to control access to one's genetic data and its use. Related terms: data security, consent. Explanation: Surrogacy contracts must address who may access the genetic results of donors, embryos, and the child, and for what purposes. Example: A clause restricts the use of the child's genome to medical care only, prohibiting research without additional consent. Challenges: Balancing privacy with future clinical utility and mandatory reporting obligations (e.g., for notifiable genetic conditions).

Genetic Risk Assessment – concept: evaluation of the probability that an individual or offspring will develop a genetic disorder. Related terms: penetrance, risk calculation. Explanation: Risk assessments guide decision-making on embryo transfer, donor selection, and disclosure policies. Example: A 25 % recurrence risk for an autosomal dominant condition influences the decision to use donor eggs. Challenges: Communicating probabilistic information clearly and managing anxiety generated by risk figures.

Genomic Sequencing – concept: high-throughput analysis of an individual's entire DNA sequence. Related terms: whole-genome sequencing, NGS. Explanation: Emerging as a tool for comprehensive embryo screening, but raises questions about data overload, incidental findings, and regulatory oversight. Example: Whole-genome sequencing identifies a rare variant of uncertain significance in an embryo. Challenges: Deciding whether to disclose incidental findings, ensuring analytic validity, and addressing cost reimbursement.

Informed Consent – concept: process ensuring participants understand the nature, benefits, risks, and alternatives of a procedure before agreeing. Related terms: autonomy, disclosure. Explanation: For genetic testing in surrogacy, consent must detail possible outcomes, confidentiality limits, and the right to withdraw. Example: A surrogate signs consent acknowledging she will not receive detailed embryo genetic reports. Challenges: Avoiding "information fatigue" when multiple consent forms are required and ensuring consent remains valid if new tests are introduced mid-cycle.

Incidental Findings – concept: genetic results unrelated to the primary reason for testing but potentially

medically significant. related terms: secondary findings, unexpected results. Explanation: Policies must dictate whether and how to disclose incidental findings to intended parents, surrogates, or the future child. Example: An embryo screen reveals a pathogenic variant for a late-onset neurodegenerative disease. Challenges: Balancing the child's future right to not know with parental desire for preparedness, and complying with jurisdictional reporting requirements.

International Surrogacy – concept: arrangement where the surrogate, intended parents, or both reside in different countries. Related terms: cross-border surrogacy, jurisdiction. Explanation: Genetic testing standards, disclosure obligations, and legal parentage rules vary widely, creating complex compliance landscapes. Example: Intended parents from Country A use a surrogate in Country B where mandatory PGT is prohibited. Challenges: Reconciling conflicting legal regimes, ensuring admissibility of genetic evidence abroad, and addressing potential exploitation.

Legal Parentage – concept: the status conferred by law recognizing an individual as a parent, granting rights and responsibilities. Related terms: statutory parent, adoption. Explanation: Genetic testing can be decisive when legal parentage is contested, especially if documentation is ambiguous. Example: Post-birth DNA testing confirms that the intended father's DNA matches the child, supporting his legal claim. Challenges: Variations in whether genetic link alone establishes parentage, and the impact of pre-birth orders versus post-birth adjudication.

Maternal-Fetal Conflict – concept: ethical tension when the genetic interests of the fetus/embryo diverge from the surrogate's preferences. Related terms: autonomy, best-interest. Explanation: A surrogate may refuse a recommended embryo transfer after learning of a high-risk genetic finding, invoking her bodily autonomy. Example: A surrogate declines to proceed with a transfer after a PGT report indicates a severe chromosomal abnormality. Challenges: Courts must weigh the surrogate's right to refuse against contractual obligations and the intended parents' reproductive interests.

Medical Necessity – concept: a standard used by insurers and courts to determine whether a procedure is essential for health. Related terms: coverage criteria, standard of care. Explanation: Genetic testing may be deemed medically necessary to prevent the birth of a child with a serious condition, affecting reimbursement. Example: An insurer approves PGT-M for a known monogenic disease in the family. Challenges: Defining "necessity" across jurisdictions, especially where the condition is late-onset or has variable expressivity.

Mosaicism – concept: presence of two or more genetically distinct cell lines within the same embryo or tissue. Related terms: chromosomal mosaicism, variant allele frequency. Explanation: Mosaicism complicates interpretation of biopsy results, leading to uncertainty about the embryo's true genetic status. Example: A biopsy shows 30% cells with trisomy 21, prompting a decision to discard or transfer. Challenges: Establishing thresholds for acceptable mosaicism, legal disputes over alleged misdiagnosis, and counseling families about uncertain outcomes.

Non-Invasive Prenatal Testing (NIPT) – concept: analysis of cell-free fetal DNA in maternal blood to screen for chromosomal abnormalities. Related terms: cfDNA, prenatal screening. Explanation: In surrogacy, NIPT can be offered to the surrogate to confirm embryo status post-transfer, but results may raise disclosure dilemmas. Example: NIPT detects a microdeletion not identified in pre-implantation testing. Challenges: Deciding whether to disclose to intended parents, managing false-positive rates, and aligning NIPT findings with earlier PGT results.

Notifiable Genetic Conditions – concept: diseases that healthcare providers are legally required to report to public health authorities. Related terms: mandatory reporting, public health. Explanation: Discovery of a notifiable condition during genetic testing may override confidentiality clauses in surrogacy contracts. Example: Detection of a pathogenic BRCA1 mutation prompts reporting under national cancer registry law. Challenges: Balancing statutory duties with contractual privacy promises and managing the impact on the child's future insurability.

Off-Label Testing – concept: use of a genetic test for an indication not approved by regulatory agencies. Related terms: experimental use, FDA clearance. Explanation: Clinics may employ off-label whole-exome sequencing to detect rare variants, raising liability concerns if results are inaccurate. Example: Using a cancer-panel assay to screen embryos for unrelated metabolic disorders. Challenges: Informed consent must disclose off-label status, and courts may scrutinize the standard of care claim.

Opt-Out Disclosure – concept: a policy allowing parties to receive genetic information unless they expressly decline. Related terms: default disclosure, consent model. Explanation: Some surrogacy agreements adopt an opt-out model for incidental findings, assuming beneficiaries want maximal information. Example: Intended parents receive a report of a carrier status unless they sign an opt-out form. Challenges: Ensuring that opt-out is truly informed and that parties are not coerced by default inclusion.

Parental Rights – concept: legal entitlements to make decisions for a child, including medical, educational, and religious choices. Related terms: custody, legal authority. Explanation: Genetic testing results can affect parental rights when a dispute arises over the child's health needs or the accuracy of disclosed information. Example: A court restricts a parent's decision to withhold treatment for a genetic condition deemed life-threatening. Challenges: Reconciling parental autonomy with the child's best-interest standard, especially when genetic information is contested.

Patrilineal Disclosure – concept: the practice of sharing genetic information primarily with the father or paternal side of the family. Related terms: paternal lineage, inheritance. Explanation: In cultures emphasizing patrilineality, intended fathers may demand full disclosure of paternal carrier status, influencing donor selection. Example: An intended father insists on a donor with no known paternal recessive traits. Challenges: Potential gender bias, conflict with surrogate's privacy, and legal mandates for equal disclosure.

Pre-Implantation Genetic Testing (PGT) – concept: laboratory analysis of embryos before uterine transfer to detect genetic abnormalities. Related terms: PGT-A, PGT-M, PGT-SR. Explanation: PGT is a cornerstone of

risk mitigation in surrogacy, allowing selection of embryos without known pathogenic variants. Example: PGT-A identifies aneuploid embryos, which are excluded from transfer. Challenges: Varying legal acceptance, cost barriers, and the ethical debate over “designer” embryo selection.

Pre-test Counseling – concept: discussion held before genetic testing to outline purpose, possible outcomes, and implications. Related terms: risk communication, consent. Explanation: Essential for surrogates and intended parents to set realistic expectations and understand limitations. Example: A counselor explains that a negative carrier screen does not guarantee a disease-free child. Challenges: Time constraints in fast-moving IVF cycles and ensuring that counseling is culturally sensitive.

Privacy Legislation – concept: statutes governing the collection, storage, and sharing of personal data, including genetic information. Related terms: GDPR, HIPAA. Explanation: Surrogacy contracts must comply with applicable privacy laws, which may dictate data retention periods and breach notification requirements. Example: Under GDPR, a European intended parent can request deletion of the child’s genetic data after a set period. Challenges: Cross-jurisdictional compliance when parties reside in regions with disparate privacy regimes.

Probabilistic Disclosure – concept: communicating genetic findings that convey risk rather than certainty. Related terms: risk communication, predictive testing. Explanation: When PGT reveals a low-level mosaicism, the report must convey probability of the child being affected. Example: A report states a 15 % chance of viable trisomy 18 cells persisting. Challenges: Avoiding misinterpretation, managing anxiety, and ensuring that the language meets legal standards for “clear and understandable” disclosures.

Qualified Geneticist – concept: a professional with specialized training and certification in genetics, authorized to interpret complex test results. Related terms: board-certified, clinical geneticist. Explanation: In legal disputes, expert testimony from a qualified geneticist often determines the credibility of test interpretations. Example: A geneticist testifies that a variant classified as “likely benign” should not have altered embryo selection. Challenges: Availability of qualified experts, potential bias, and differing classification standards (e.g., ACMG vs local guidelines).

Reproductive Rights – concept: the legal protections guaranteeing individuals the freedom to make decisions about reproduction. Related terms: bodily autonomy, pro-creation. Explanation: Genetic testing policies intersect with reproductive rights when restrictions limit access to certain tests or impose mandatory disclosure. Example: A jurisdiction bans PGT for non-medical traits, citing concerns over eugenics. Challenges: Balancing individual autonomy against societal values and anti-discrimination principles.

Research Ethics – concept: moral principles governing the conduct of scientific investigations involving human subjects. Related terms: informed consent, IRB. Explanation: Using surplus embryos for genetic research requires clear consent and compliance with national regulations. Example: A clinic submits an ethics application to study the prevalence of rare copy-number variants in discarded embryos. Challenges:

Ensuring that consent covers future unspecified research and addressing public concerns about “embryo commodification.”

Risk Communication – concept: the process of conveying probabilistic health information in a way that is understandable and actionable. Related terms: health literacy, counseling. Explanation: Effective risk communication is vital when discussing carrier status, mosaicism, or incidental findings with intended parents. Example: Using visual aids to illustrate a 1 in 250 chance of an autosomal recessive disease. Challenges: Overcoming numeracy gaps, cultural differences in risk perception, and avoiding undue alarm.

Segregation Analysis – concept: a genetic method that assesses inheritance patterns within a family to interpret variant significance. Related terms: pedigree analysis, co-segregation. Explanation: When a variant of uncertain significance (VUS) is identified in a donor, segregation analysis can help determine pathogenicity before embryo selection. Example: Testing extended family members shows the variant co-segregates with disease, upgrading its classification. Challenges: Access to family members, privacy considerations, and time constraints in IVF cycles.

Self-Disclosure – concept: the act of an individual voluntarily revealing personal genetic information. Related terms: autonomy, voluntary reporting. Explanation: Surrogates may choose to disclose their own carrier status to intended parents, influencing donor selection or embryo transfer decisions. Example: A surrogate informs the clinic that she is a carrier for thalassemia, prompting a donor-egg recommendation. Challenges: Ensuring that self-disclosure does not lead to coercion or discrimination.

Sex Selection – concept: choosing the sex of an embryo through genetic or procedural methods. Related terms: gender preference, ethical controversy. Explanation: Some jurisdictions prohibit sex selection for non-medical reasons, affecting surrogacy contracts that include such preferences. Example: Intended parents request PGT-A to select a female embryo for cultural reasons. Challenges: Legal enforcement, ethical debates about gender bias, and potential discrimination claims.

Single Nucleotide Polymorphism (SNP) Array – concept: a technology that assesses thousands of SNPs across the genome to detect copy-number changes and genotype. Related terms: microarray, genotyping. Explanation: SNP arrays are commonly used for PGT-A to screen for aneuploidies and large deletions. Example: A SNP array reveals a 5 Mb deletion on chromosome 22q11.2. Challenges: Interpreting the clinical relevance of detected copy-number variants and managing incidental findings.

Sperm Donation – concept: provision of sperm by a donor for use in assisted reproduction, often anonymized. Related terms: donor anonymity, gamete procurement. Explanation: Genetic testing of donor sperm can uncover carrier status for autosomal recessive diseases, affecting embryo risk. Example: Carrier screening identifies a donor sperm sample with a pathogenic CFTR mutation. Challenges: Balancing donor privacy with the child’s right to health information and navigating differing national regulations on donor disclosure.

Stem Cell Research – concept: scientific investigation involving pluripotent cells derived from embryos or induced sources. Related terms: embryonic stem cells, iPSCs. Explanation: Surplus embryos from surrogacy cycles may be donated to stem-cell research, requiring explicit consent and compliance with ethical guidelines. Example: A clinic establishes a program to derive iPSCs from discarded embryos for disease modeling. Challenges: Public perception, consent clarity, and ensuring that research use does not conflict with future parental claims.

Statutory Birth Registration – concept: the legal requirement to record a child's birth details, including parentage, in a government registry. Related terms: civil registration, vital records. Explanation: In surrogacy, the names entered on the birth certificate may differ from genetic parentage, creating potential legal conflicts. Example: Intended parents are listed as "mother" and "father" on the certificate despite the surrogate's gestational role. Challenges: Aligning registration practices with genetic evidence and respecting the surrogate's legal rights.

Storage Consent – concept: permission granted for the long-term preservation of embryos, gametes, or DNA samples. Related terms: biobanking, cryopreservation. Explanation: Contracts must specify duration, access rights, and conditions for destruction of stored materials. Example: Intended parents sign a storage consent allowing embryos to be kept for up to ten years. Challenges: Changing circumstances (e.g., divorce) that affect who may access or dispose of the material, and regulatory limits on storage time.

Surrogate Compensation – concept: financial remuneration provided to a woman who carries a pregnancy for another party. Related terms: gestational carrier, payment. Explanation: Compensation structures may be linked to genetic testing outcomes, such as additional fees for extensive PGT panels. Example: A contract includes a surcharge for whole-genome sequencing of embryos. Challenges: Ensuring that compensation does not become a coercive incentive to consent to invasive testing.

Surrogate Disclosure Obligations – concept: legal duties of the surrogate to share relevant health or genetic information with intended parents. Related terms: duty to inform, communication. Explanation: A surrogate may be required to disclose her own carrier status or any prenatal test results that affect the child's health. Example: A surrogate informs the intended parents that NIPT detected a microdeletion not seen in PGT. Challenges: Determining the scope of disclosure, respecting the surrogate's privacy, and managing conflicting interests.

Therapeutic Misconception – concept: the mistaken belief by participants that a clinical procedure is primarily intended to benefit them personally, rather than to generate knowledge. Related terms: misconception, clinical trial. Explanation: In research-linked surrogacy, intended parents may think that experimental genetic testing guarantees a healthy child. Example: Parents enroll in a trial offering novel CRISPR-based embryo editing, believing it ensures disease-free offspring. Challenges: Clear communication to prevent unrealistic expectations and legal liability for misleading claims.

Third-Party Reproduction – concept: reproductive assistance involving individuals other than the intended

parents, such as donors or surrogates. Related terms: donor conception, gestational carrier. Explanation: Genetic testing policies must address the rights and responsibilities of all third parties involved. Example: A donor egg is screened for mitochondrial DNA mutations before use. Challenges: Coordinating consent and disclosure among multiple parties and navigating differing legal definitions of parenthood.

Thoroughbred Ethics – concept: an informal term describing the pressure to produce “optimal” offspring through selective genetics, analogous to animal breeding. Related terms: eugenics, designer babies. Explanation: In high-net-worth surrogacy arrangements, there may be an expectation to use extensive genetic screening to achieve “perfect” traits. Example: Intended parents request PGT for polygenic scores related to height and intelligence. Challenges: Lack of robust scientific evidence, ethical condemnation, and potential legal bans on non-medical trait selection.

Transfer Eligibility – concept: criteria determining whether an embryo may be transferred based on genetic and morphological assessments. Related terms: embryo grading, selection policy. Explanation: Clinics often set thresholds for aneuploidy percentage, mosaicism level, and VUS burden before proceeding. Example: Embryos with >50 % mosaic cells are deemed ineligible for transfer. Challenges: Legal disputes when intended parents disagree with the clinic’s eligibility standards.

Turn-key Surrogacy Service – concept: a comprehensive package offered by a provider that includes donor matching, genetic testing, legal drafting, and pregnancy management. Related terms: full-service agency, bundled offering. Explanation: Such services must ensure that all genetic testing components comply with the relevant laws of the parties’ jurisdictions. Example: A provider includes mandatory carrier screening for both donors and intended parents in its contract. Challenges: Regulatory oversight across multiple service areas and liability for any testing error.

Undue Influence – concept: improper pressure exerted on a party to obtain consent, potentially rendering the agreement voidable. Related terms: coercion, duress. Explanation: In surrogacy, a surrogate may feel compelled to consent to extensive genetic testing due to financial dependence. Example: A surrogate signs a consent form for embryo biopsy after being told payment will be withheld otherwise. Challenges: Proving undue influence in court and ensuring that consent processes are free from coercive elements.

Uptake Rate – concept: the proportion of eligible individuals who elect to undergo a particular genetic test. Related terms: participation, acceptance. Explanation: Monitoring uptake helps assess whether counseling and consent processes are effective. Example: Only 60 % of intended parents opt for expanded carrier screening despite recommendation. Challenges: Identifying barriers such as cost, cultural beliefs, or fear of discrimination.

Variant of Uncertain Significance (VUS) – concept: a genetic alteration whose impact on disease risk is unclear. Related terms: ambiguous result, classification. Explanation: VUS findings in embryos present a dilemma for transfer decisions and disclosure policies. Example: An embryo carries a VUS in the MYH7 gene linked to cardiomyopathy. Challenges: Deciding whether to transfer, how to counsel parents, and potential

legal liability for undisclosed risk.

Whole-Exome Sequencing (WES) – concept: sequencing of all protein-coding regions of the genome to detect pathogenic variants. Related terms: exome, next-generation sequencing. Explanation: WES may be employed for comprehensive monogenic disease screening in embryos, but raises cost and interpretation issues. Example: WES identifies a pathogenic mutation in the DMD gene in an embryo. Challenges: Determining clinical relevance, managing incidental findings, and ensuring test validation for the low-DNA quantity of biopsies.

Write-Off Clause – concept: a contractual provision allowing parties to terminate the agreement without penalty under specific circumstances, such as adverse genetic findings. Related terms: termination clause, exit provision. Explanation: A write-off clause may be triggered if PGT reveals a non-viable embryo, permitting reimbursement of expenses. Example: Intended parents invoke the clause after all embryos are deemed aneuploid. Challenges: Drafting clear triggers, preventing abuse, and aligning with consumer-protection statutes.

Y-Chromosome Analysis – concept: testing that focuses on the male-specific region of DNA to determine paternal lineage. Related terms: paternal haplogroup, forensic DNA. Explanation: Y-chromosome data can confirm the genetic contribution of the intended father or sperm donor. Example: A Y-STR profile matches the intended father, supporting his legal claim. Challenges: Limited utility for disease risk, potential privacy concerns, and varying admissibility standards in court