Chapter

1

# Introduction

In February 2024, the Alabama Supreme Court issued a ruling that sent shock waves through the world of reproductive medicine. In a wrongful-death case, the court held that frozen embryos created through in vitro fertilisation (IVF) count as 'children' under state law (Gunther 2024). The ruling cited no new biomedical evidence; it did not reassess IVF outcomes or safety. Yet, within days, multiple fertility clinics in Alabama suspended IVF treatments. Physicians and clinic directors faced an impossible question: could routine practices such as freezing, discarding, or genetically testing embryos now expose them to criminal liability under child-protection statutes? The answer was unclear. In that moment of uncertainty, care stopped being the main concern.

What makes this moment so revealing is not simply the legal decision itself, but how medical knowledge was translated into law and then retranslated back into clinical practice. The court's ruling depended on a particular narratively constructed translation of embryological facts: embryos were no longer treated as potential life within a medical process, but as legal persons with full moral standing. This narrative re-emplotted IVF, reframing it not as a standard reproductive technology governed by professional guidelines and risk management, but as a domain of child welfare in which avoiding potential harm was a priority. Clinicians, in turn, were forced to translate that legal narrative back into their daily work. Established clinical guidelines, laboratory protocols, and ethical frameworks developed over decades in reproductive medicine suddenly no longer aligned with the story the law was telling about embryos, responsibility, and risk. The science had not changed, but its meaning had. Public reactions revealed yet another layer of translation: US president Joe Biden condemned the ruling as 'outrageous and unacceptable' (Chidi 2024), while former US president Donald Trump urged lawmakers to intervene to protect access to IVF (Piper 2024). Media coverage framed the event variously as a threat to family building, a victory for fetal rights, or a legal overreach. In each narrative, the same underlying biomedical evidence was mobilised into different worlds of meaning. This cascade of translations – from clinic to courtroom to public discourse – encapsulates the central concern of this book: how narratives shape the travel of medical knowledge and why a narrative model of knowledge translation (KT) offers vital insights for contemporary healthcare.

## 1.1 Beyond the Bedside: Narrative Medicine Meets Knowledge Translation

The main objective of this book is not simply to extend narrative medicine beyond the bedside and the individual clinical encounter, but to critically rework its



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conceptual foundations in order to show how narrativity operates across the full landscape of medical KT. While acknowledging the strengths of narrative medicine, we point to a number of important limitations and lacunae that require extensive rethinking. We offer a broadened conceptualisation of narrativity and demonstrate its ability to inform nuanced, critical analyses of three key areas of reproductive health: puberty blockers for transgender youths, mosaic embryos in IVF treatments, and the highly contested topic of abortion.

Often associated with the empirical, scientific dimension of medicine, KT seeks to bridge the gap between medical research and practical application, aiming to move 'bench to bedside' (van der Laan and Boeninik 2015). It emphasises implementing evidence-based findings, thereby ostensibly resolving tensions between science and culture in favour of evidence-based paradigms. Narrative medicine, on the other hand, has typically focused on the humanistic and cultural dimensions of care, largely emphasising the individual patient's experience and story (often within that patient's specific cultural context). In its classic formulation, narrative medicine is about clinicians listening to patient stories to foster empathy, reflection, and compassionate, personalised care (Solomon 2015). This focus on personal experience and patient storytelling has created a perception of narrative medicine as the 'art' side of medicine, something set apart from, or even in opposition to, the rigorous scientific methodologies of evidence-based medicine (EBM).

This book challenges the entrenched dichotomy of 'art versus science' in medicine. We argue that narrative medicine can serve a broader and more integrative function, opening novel avenues for understanding and applying medical knowledge. But there is a need to first expand its purview (the clinical encounter) and rethink some of its key assumptions – for example, the assumption that narratives are inherently benign and empowering. Rather than viewing the narratives of patients and the data of scientists as two separate domains, we seek in this book to bring both parts of the story together – the story of the science and the story of the patient as embedded in cultural and social contexts. By doing so, we propose ways to overcome a long-standing and unhelpful split between medical humanities and medical science.

Our approach is inspired in part by the emerging field of **translational medical humanities (TMH)**, described recently as a 'third wave' in medical humanities scholarship (Bleakley 2023). The field of TMH builds on earlier critical approaches to medicine (the 'second wave' that exposed epistemological, ethical, and political assumptions of biomedicine), but it couples critique with a constructive ambition. It uses the lens of translation to examine how biomedical and cultural forms of knowledge move across domains. In other words, TMH asks not only what knowledge is produced in medicine but how it is translated – interpretively, textually, narratively – from labs to guidelines to clinics to publics. This perspective questions the notion that medical knowledge is a stable entity that simply needs to be delivered or disseminated. Instead, knowledge is seen as the outcome of ongoing, collective meaning-making among diverse actors (researchers, clinicians, policymakers, patients, institutions, publics). From a TMH standpoint, translating medical research into practice is never a purely technical or linear process; it necessarily involves interpretation, recontextualisation, and narrative reframing as evidence is



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redeployed in new settings. Medical knowledge is not a solid package to be transferred intact but a fluid narrative that changes shape as it travels.

Taking this translational humanities framework as a starting point, we advance a **narrative model of KT**. This approach treats narrative as a core medium of translation and insists that narrativity is constitutive of medical knowledge at every stage, rather than principally in the clinical encounter. Moving beyond the bedside does not mean abandoning narrative medicine's humanistic ethic; rather, it means extending it into the systemic processes by which medical knowledge is produced, evaluated, and implemented. Narrative is not merely an add-on for better communication at the end of the research pipeline; it permeates the entire pipeline. As the historian Hayden White famously observed, narrative is the solution to 'the problem of how to translate knowing into telling' (White 1980:5). We take this insight literally: translating scientific knowing into telling (in papers, guidelines, policies, and public messages) always requires narrative work. Narratives are meta-codes that operate across all forms of discourse; even scientific reports rely on narrative structures to render data into meaningful knowledge. Real-world events and research findings do not present themselves as self-interpreting stories or facts; we comprehend them by placing them into narrative frameworks of cause and effect, conflict and resolution, value and meaning.

In bringing narrative medicine's insights to bear on KT by rethinking and extending some of its main tenets in our own narrative model of knowledge translation, our aim is twofold. First, we seek to expand narrative medicine's scope by investigating how a narrative approach can enhance KT across all stages of the translational process, not just in the clinician's office. Traditionally, translation in medicine is described as a series of stages: basic research findings move into clinical trials, then into systematic reviews and guidelines, and finally into clinical practice. However, this dominant conception of the translational chain frames it as a purely scientific and methodological progression, overlooking the essential role of texts, narratives, and interpretation at each step. In reality, at every stage of the journey from bench to bedside, knowledge is mediated by a variety of narratively constructed spoken and written texts: grant proposals define what questions get asked; research articles and conference presentations shape how findings are understood; systematic reviews and guidelines repackage evidence for broader audiences; and finally policy briefs, clinical protocols, and patient education materials translate evidence into actionable advice. Each of these textual forms involves choices about framing and storytelling. Scientific findings do not simply speak for themselves as they move through this chain; they are continually re-narrated through regulatory documents, peer-reviewed papers, consensus statements, and a variety of public health communications. Each translation requires interpretation by its authors and readers, framed by narrative constructions that influence how the evidence is perceived and applied. Yet, until now, narrative medicine has been largely confined to the final stage of this chain – the clinical encounter – while the preceding stages (often cast as 'pure science') are regarded as narrative-free zones. Even scholars who recognise the value of narrative in the domain of medicine have tended to focus on improving communication with patients; examples include proposals for a 'narrative evidence-based medicine' to bridge research-to-practice gaps. Such efforts remain within



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a paradigm that separates 'science' (the early stages of research and evidence synthesis) from 'story' (the later stage of clinical application). By contrast, we insist on the integral role of narrative throughout all phases of translational science. We argue that narrative inquiry can illuminate the hidden interpretive work at play in every step of knowledge production and implementation, from the lab scientist's framing of a hypothesis to the guideline panel's justification of a recommendation.

Further, we aim to offer a more nuanced understanding of KT itself. Rather than viewing KT as a technical process of packaging and transmitting neutral facts, we demonstrate that it is fundamentally structured by narrative logics and storytelling practices. In Walter Fisher's terms (1987:49), 'no matter how strictly a case is argued – scientifically, philosophically, or legally – it will always be a story, an interpretation of some aspect of the world'. Medical evidence is never just a collection of data points awaiting transfer; it is always embedded in an ongoing narrative of human significance. This means that whenever knowledge is translated (say, from a clinical trial to a guideline or from a guideline to a policy), it undergoes narrative transformation. Different narrative framings can lead to very different practical outcomes, even if the underlying data remain the same. By recognising and critiquing these narrative choices, we can better understand controversies in medicine and perhaps improve how we handle them. Our approach aligns with what we describe in the concluding chapter (Chapter 7) as deep KT – a reflexive practice that interrogates the formats, values, and storylines through which evidence is made meaningful. Such an approach asks fundamental questions often ignored in conventional KT. What counts as knowledge here? Through which narrative formats is it made intelligible? What assumptions and values are embedded in these formats?

## 1.2 Narrative, Evidence, and Power: Why Stories Matter Now

We ground our theoretical argument in a specific domain of medicine: reproductive and sexual health. We focus on three interrelated areas as case studies: puberty blockers for transgender youth, IVF (in particular, embryo selection and policy), and abortion. We chose this domain because it starkly exposes the entanglement of scientific knowledge with societal values, and it exemplifies how narrative mediates that entanglement. In each of these areas, debates over medical interventions are not only about data; they are about how data are interpreted, framed, and assigned meaning in different contexts. Decisions about reproductive and sexual health have far-reaching moral, cultural, and political implications. Consequently, the narratives that guide the translation of evidence in these areas often become explicit flashpoints. Are puberty blockers a standard treatment for a recognised condition or an experimental risk foisted on vulnerable youths? Is an embryo a patient, a 'child', or a cluster of cells? Is abortion a matter of public health and rights, or a moral transgression to be curtailed? These questions cannot be settled by evidence alone because they arise from deeper narrative worldviews.

Importantly, attending to the narratives of science in this field means recognising that scientific knowledge itself is constructed, communicated, and interpreted within cultural and political contexts. Scientific narratives are never completely neutral or



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objective; they are shaped by the values and assumptions of the researchers and institutions that produce them. The history of reproductive health science bears this out. For example, biases related to gender, race, and socio-economic power have long influenced which questions are asked and which populations are prioritised. (One telling statistic: Black women are about 50% less likely to be diagnosed with endometriosis than white women, due in part to barriers in gynecological care and systemic biases regarding whose pain is recognised (Farland and Horne 2019).) Understanding the narratives underlying 'factual' knowledge allows us to see how certain values (autonomy, justice, sanctity, etc.) come to be prioritised or silenced in medical debates. Different stakeholders (clinicians, patients, activists, policymakers) may be driven by different core narratives – for instance, a narrative of patient autonomy versus a narrative of protecting the vulnerable. These value-laden narratives influence how evidence is produced, disseminated, and applied, determining who benefits from healthcare advances and who is marginalised or left behind. By complementing narrative medicine's traditional focus on 'the recognition of singularity, respect for illness's mystery, and attention to the embodied self' (Charon and Wyer 2008:297), with a Foucauldian attention to the broader narratives and power structures underpinning population-level policies, we can reveal how ostensibly objective medical facts are narratively constructed and hence open to being deployed to serve a range of often-conflicting agendas.

We are, in fact, living through a moment in medicine where the loudest conflicts are no longer about data gaps but about how evidence should be interpreted, narrated, and acted upon. The controversies surrounding gender-affirming care for trans youth (puberty blockers), IVF, abortion, and even vaccination are not simply scientific debates – they are narrative battles over meaning and values. In all three of our in-depth case studies (puberty blockers, IVF genomics, and abortion care), several common features stand out:

- **Evidence is evolving:** the scientific evidence base is partial but growing, and uncertainty remains openly acknowledged.
- **Urgency amid uncertainty:** decisions cannot wait for perfect evidence. Policy and clinical decisions are urgent, moralised, and politically charged, despite the scientific uncertainty.
- **High stakes and polarisation:** each case has become a proxy for larger ideological conflicts – questions of family, gender, autonomy, and ethics that polarise public opinion.

What makes these cases especially salient is that they expose a structural problem in contemporary medicine: our prevailing models of KT are not equipped to handle deep moral disagreement under conditions of uncertainty. These issues are sometimes treated as exceptional (Cahill 2020), but we argue that their dismissal as such misses the point. Rather than being the exception, these controversies function as stress tests for EBM itself. They reveal what happens when

- Evidence is incomplete, yet action cannot wait.
- Values are plural and irreconcilable.
- Guidelines must function within complex political and cultural ecosystems.



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If our current KT frameworks cannot cope in these high-pressure scenarios, they are likely failing in other areas too – just less visibly. In this sense, the reproductive health cases are harbingers: they dramatise challenges that are increasingly common in medicine. For decades, EBM rested on a promise: as evidence accumulates, uncertainty will recede and consensus will emerge. But in domains like IVF or gender-affirming care or abortion, uncertainty has not receded – it has proliferated and must be managed as a permanent condition of decision-making. Paradoxically, advances like genomic testing in IVF produce more questions and finer-grained uncertainties, not less. Long-term outcomes such as effects of puberty suppression, or population impacts of reproductive policies, remain ethically charged yet empirically unresolved. And still decisions must be made – by clinicians with patients in the room and by policymakers drafting laws. Uncertainty is no longer an aberration to be eliminated by more data; it is the normal backdrop of medical practice.

This is where a narrative approach to KT becomes essential. When evidence alone cannot dictate a clear course, translation becomes a matter of storytelling rather than just technical transfer. In our case studies, we see that clinical guidelines and evidence syntheses do not remain confined to clinics or journals; they rapidly enter public arenas. An IVF guideline or a puberty blocker evidence review is cited in courtrooms, mobilised in parliamentary debates, invoked by advocacy groups, and amplified by media reporting. In short, KT has become a form of governance, whether intended or not. The narrative framing of an evidence-based guideline can determine whether it is taken up to expand services or to restrict them, whether it bolsters patient autonomy or enforces precaution, whether it appears compassionate or coercive. For example, a guideline on abortion framed as a public health imperative with human-rights language will be received very differently from one framed in purely technical terms – it might be celebrated in some contexts and attacked as 'ideology' in others. Likewise, a narrative of caution around puberty blockers (emphasising unknown risks) empowers certain actors (regulators, protective parents), while a narrative of affirmation (emphasising youths' agency and known benefits) empowers others (gender-affirming clinicians and trans advocates). Our critical perspective shows that understanding narrative at the translational level is no longer optional – it is necessary to prevent evidence from being politically weaponised without accountability. By illuminating how stories and values infuse every step from data to policy, we can better grasp why certain scientific conclusions lead to public outcry or legislative backlash and, conversely, how more reflexive narrative practices might foster dialogue over polarisation.

## 1.3 Methodology and Structure of This Book

Although we define narrative broadly (beyond just written text), the primary material for our analysis in this book is written texts produced during the process of KT. Each of the following chapters focuses on a specific kind of translational text – for example, a clinical guideline, a systematic review, or a policy report – and examines how that text frames medical knowledge narratively.

The analytical focus varies across the three empirical chapters in response to the specific role that evidence plays in each case. In the first empirical chapter, Chapter 4,



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the primary concern is how the Cass Review is interpreted, contested, and mobilised by both critics and supporters. This reflects the chapter's orientation toward evidence review as a particularly unstable and high-stakes translational moment, in which evidentiary claims do not yet function as settled guidance but instead generate competing calls for action across clinical, political, and public arenas. By contrast, Chapter 5 examines two competing clinical guidelines and analyses how divergent sets of recommendations translate the same underlying evidence into different normative and practical orientations, thereby shaping professional judgement and public debate. Chapter 6 focuses on a single authoritative guideline and investigates how it operates to manage, contain, and stabilise a long-standing controversy by consolidating epistemic and moral authority.

These differences in analytical focus are deliberate: they reflect our interest in tracing narrative dynamics at distinct stages of KT – when evidence is contested, when it is pluralised into competing recommendations, and when it is consolidated into institutional authority – while maintaining a common analytical commitment to narrative as a central mechanism through which medical knowledge acquires meaning, force, and consequences.

We undertake close textual readings to unpack the narrative structure and assumptions of these documents, and then trace how these narratives are recoded and contested as the text circulates through different debates and communities. In doing so, we use a close-reading narrative approach (detailed in Chapter 2) that attends to narrators, protagonists, patterns of selective appropriation, temporality, emplotment, and genericness in order to reveal the values and assumptions built into each text. This close reading represents the core of the analysis, since each chapter focuses on either a single text (the Cass Review in Chapter 4 and the World Health Organisation's (WHO's) *Abortion Care Guideline* in Chapter 6) or at most two texts (the recommendations of the American Society for Reproductive Medicine (ASRM) and the Preimplantation Genetic Diagnosis International Society (PGDIS) on the use of mosaic embryos in Chapter 5). Where appropriate, we supplement this close analysis with distant reading techniques based on identifying and accounting for recurrent patterns in our chosen texts. These texts form part of a large corpus of health care and policy documents: the **Sustainability and Health Corpus (SHE Corpus)** developed at the Centre for Sustainable Healthcare Education.[1] The focus on sustainability in the SHE Corpus reflects an understanding aligned with the United Nations' Sustainable Development Goals, in which sustainable healthcare is not limited to environmental impact but encompasses the durability of evidence practices, social justice, and inclusiveness in how medical knowledge is produced and applied, and the capacity of health systems to manage uncertainty and plural values over time.

The SHE Corpus was developed in part through a three-year project funded by the UiO:Democracy initiative at the University of Oslo. **MEDRA** (the **Medicalisation of Democratic Rights in the Debate about Abortion** in the US, Ireland, and Argentina) explores how evidence is mobilised in medical, legal, and civil society

[1] www.shecorpus.net.



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debates about abortion.[2] Many key texts on reproductive health are included in this large, multi-million-word corpus, including the Cass Review (the subject of Chapter 4) and the WHO guideline (Chapter 6). Access to the SHE Corpus and accompanying software interface allows us to search for and identify recurring conceptual patterns and shifts in language across different texts or in a single text – patterns and shifts that either support a particular claim by advocates or detractors of each narrative (as in the case of the Cass Report) or reveal and provide evidence for a tension in the narrative that undercuts its internal logic (as in the WHO guideline). By combining qualitative narrative analysis with computational tools, we capture both the granular detail of particular translational narratives and the broader discursive trends in the field. This mixed methodology allows us to see what weight a certain guideline gives to different elements of a narrative and how it narrates its protagonists, among other things, which provides us with some insight into the extent to which it echoes or deviates from prevailing narratives in the relevant debate.

In the following chapter (Chapter 2), we establish the theoretical groundwork for the book by reconceptualising narrativity in medicine and offering a critical reassessment of narrative medicine as a backdrop to this reconceptualisation. We advance a broad understanding of narrative as a fundamental process of sense-making that shapes not only clinical encounters but also scientific research, evidence production, and policy formation. Challenging narrative medicine's predominant focus on individual patient stories, the chapter shows how this narrow framing obscures institutional, conceptual, and metanarratives, as well as the power relations and value judgements embedded in every instantiation of medical knowledge. After demonstrating that scientific texts such as trials, reviews, and guidelines are themselves narratively structured, the chapter proceeds to outline a flexible typology of narratives alongside a critical analytic toolkit that is used throughout the book to examine how medical knowledge is constructed, translated, and contested.

Chapter 3 builds on this conceptual foundation by reframing KT as a narrative and political practice, rather than a purely technical process of evidence transfer. Tracing the emergence of KT alongside translational research and EBM, the chapter shows how dominant KT frameworks inherit epistemic hierarchies that privilege standardised genres such as randomised controlled trials, systematic reviews, and clinical guidelines, while obscuring the interpretive, value-laden, and power-sensitive work involved in translating knowledge across contexts. It argues that translational texts are not stable end-points but generative sites of ongoing re-narration, and that prevailing KT models tend to marginalise local, experiential, and non-Western forms of knowledge. This critique sets the stage for a more reflexive, narrative-informed rethinking of KT developed in subsequent chapters.

Chapters 4 to 6 develop this rethinking through a series of empirical case studies in reproductive and sexual health, each illustrating how narrative framing shapes the meaning, authority, and consequences of translated medical knowledge. Chapter 4 analyses the contested narratives surrounding puberty blockers for transgender youth, focusing on the 2022–2024 Cass Review and its aftermath as a key site of

[2] www.uio.no/english/research/strategic-research-areas/democracy/research/groups/the-medicalisation-of-democratic-rights-in-the-deb/index.html.



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KT and re-narration. The chapter shows how the Cass Review constructs a dominant narrative of evidentiary uncertainty and risk by privileging systematic reviews and randomised trials, selectively emphasising gaps in evidence, and framing transgender youth as a vulnerable and exceptional population requiring heightened caution. It traces how this narrative has been taken up, challenged, and transformed by clinicians, activists, policymakers, courts, and media actors, generating competing storylines that alternately emplot puberty blockers as dangerous, experimental interventions or as necessary, affirming care. In doing so, the chapter demonstrates how translational texts can marginalise lived experience, foreground particular epistemic values, and produce far-reaching consequences for policy and practice.

Chapter 5 turns to IVF and genomic testing, examining how advances in preimplantation genetic testing for aneuploidy (PGT-A) destabilise binary notions of embryonic normality and generate new narrative and ethical uncertainties around mosaic embryos. Focusing on the evolving guidelines of the ASRM and the PGDIS, the chapter shows how the same body of scientific evidence is translated into two divergent narrative frameworks: one aligned with precision medicine, emphasising optimisation, stratification, and technological promise, and another grounded in EBM, foregrounding uncertainty, prudence, and patient autonomy. By tracing how mosaic embryos are narratively reclassified – from non-viable abnormalities to contingent possibilities – the chapter demonstrates how guidelines function as mediating texts that do not resolve uncertainty but redistribute interpretive responsibility among laboratories, clinicians, and patients. The analysis highlights how competing narratives of precision and prudence shape clinical decision-making, ethical judgement, and public debate.

Chapter 6 examines the WHO's 2022 *Abortion Care Guideline* as a powerful site of narrative authority and contestation in global health governance. Treating the guideline not as a neutral technical document but as a value-laden institutional narrative, the chapter analyses how the WHO constructs epistemic and moral authority by combining systematic evidence appraisal with a human-rights framework, narrating abortion primarily as an issue of health, safety, and access. It traces how this narrative assigns agency to pregnant persons, frames restrictive laws and conscientious objection as systemic barriers, and emplots abortion care within a progressive storyline of public health improvement. At the same time, the chapter examines counter-narratives that challenge the WHO's legitimacy; recentre fetal life, conscience, and national sovereignty; and recast the guideline as ideological overreach. By unpacking these competing narrative configurations, the chapter shows how global health recommendations acquire – or lose – normative force through narrative framing rather than evidence alone.

Finally, Chapter 7 draws these conceptual and empirical threads together by articulating a narrative model of KT grounded in TMH. Moving beyond the bedside-focused remit of narrative medicine, the chapter argues that narrativity is constitutive of medical knowledge at every stage of translation – from research and evidence synthesis to guidelines, policy, and practice. It synthesises the insights generated across the case studies to identify recurring tensions, blind spots, and risks within prevailing KT models, particularly the paradox between contextual sensitivity and abstraction. The chapter concludes by formulating seven principles of deep KT,



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which assert that narrativity is constitutive of KT, foreground epistemic reflexivity, narrative plurality, contextual accountability, traceability, and ethical responsibility as core virtues for a more transparent, inclusive, and critically attuned approach to translating medical knowledge. We propose that knowledge derived from the humanities does not replace scientific evidence: instead, it performs the crucial task of revealing and informing the process of how evidence is narrated, contextualised, and re-narrated in new contexts.



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