



Tempering hype: bioethics as a 'critical friend' of emerging technologies



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My aims today:

To suggest how analysis of certain concepts in bioethics can help us to have a deeper and more nuanced debate over regulation of emerging technologies

To suggest some of the ways in which bioethics scholarship can go awry – as a pointer to what we should avoid doing

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Structure:

1. The innovation landscape
2. Agendas and challenges
3. Four ways that bioethics can go wrong
4. A role for bioethics in effective regulation



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1. The innovation landscape



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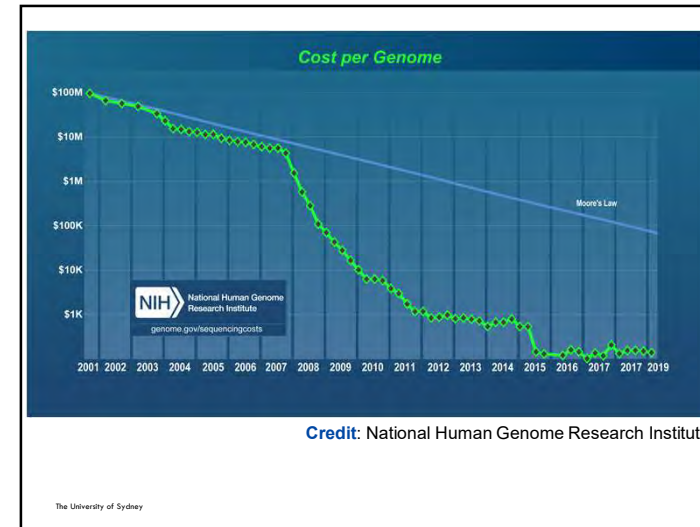
Enthusiasm for new therapies...

- **Ethical framings of the technology** (applying Hofmann, 2009)
 - Hopeful principle
 - Appeals to technology
 - Appeals to widespread belief
- **Also prevalent:**
 - Prevalence of (and bias towards) pro-tech arguments
 - Valorisation of information



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From genetics to genomics

From this...	To this... (???)
People offered testing due to their family history or age	Everyone offered testing
Testing provided by specialists	Testing via range of health professionals (or DTC)
Single gene condition or small group of aneuploidies	WGS
'Coarser' information	More fine-grained information



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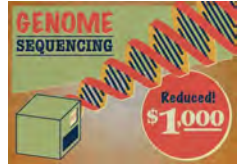
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Before we get too excited...

When implementing emerging technologies, it is important to be aware of limits to knowledge

Example: Genomics

- We still don't know what a lot of the genome does
 - Genomic data remains a poor predictor of overall health
- Not all genes are penetrant
 - And some we thought were, aren't
- Interpretation databases remain imperfect

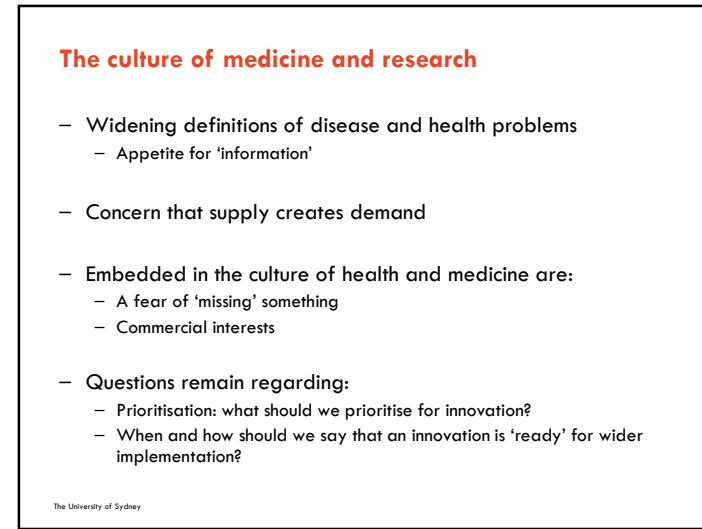


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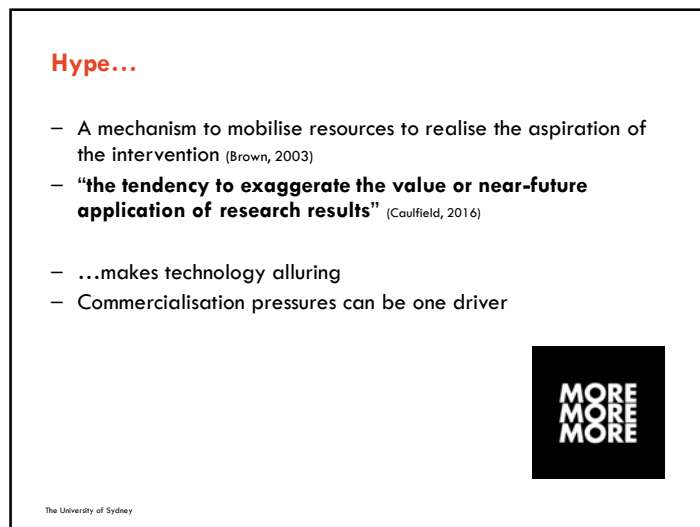
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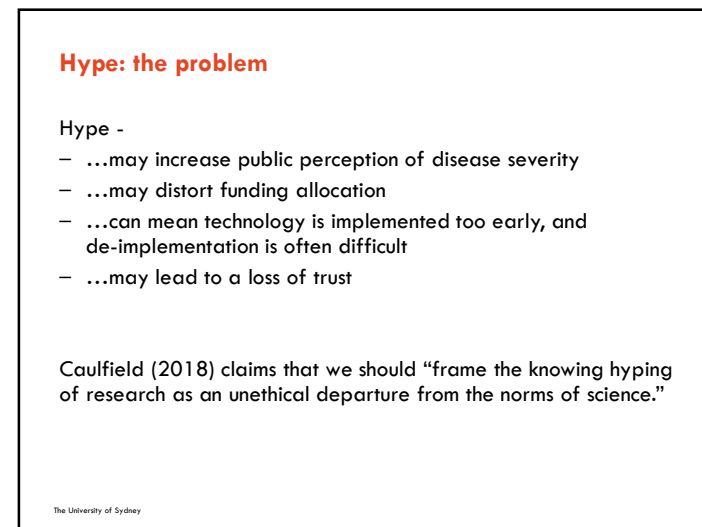
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Empowerment

- Individuals exerting independent control over a particular health intervention
 - Power, control
 - Emphasis on individual choice
 - Emphasis on taking responsibility
- A rhetoric of 'empowerment' is prevalent in many health systems

Credit: Mervyn Chan; Unsplash



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Concerns with empowerment

- Empowerment can **move responsibility** for health away from the state and **on to patients**
 - This shift has not been made consciously
 - Fairness, health literacy, social determinants of health
- Empowerment can **move power** from public to **corporate institutions** (e.g. personal genomics market)
- Does empowerment **overly responsabilise** individuals, at the expense of clinical leadership? (Chiapperino & Tengland, 2015)

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3. Four ways that bioethics can go wrong



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Why isn't bioethics doing as well as it could?




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Problem 1: Uncritical Acceptance of Technology

- Scholars in bioethics can assume perfect technologies
- While thought experiments are fine, such examples are then taken up by others outside our discipline
 - Used to justify implementation
 - Concepts become shallow (e.g. autonomy)
- Risks missing the ethical relevance of limits to technologies





Photo by [Holger Link](#) on [Unsplash](#)

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Problem 2: Arguing within limited parameters

- If **harm < benefit**, then 'full steam ahead'
 - Yet this approach is too narrow, and will inevitably lead to technology being introduced.
 - It also ignores the distribution of benefits and harms (they can fall on different parties)
- If **provide full information**, then obligations to patients are met
 - This is not how people actually behave



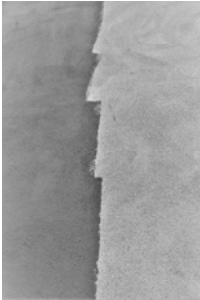
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Problem 3: Dichotomising the debate

- In bioethics, often the most significant debates happen at the 'poles'
- There is less debate on the 'middle ground'
- This is exacerbated by pressures such as grant funding and gaining media attention – hard to be nuanced
- Attempting to take the middle ground can lead to criticism from both sides



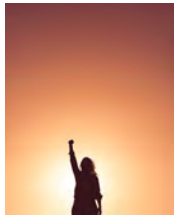
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Problem 4: the problem of the perfect patient

- People and patients are viewed as highly resourced, health literate individuals living in high income settings, with little or no interdependencies
- With technologies such as genomic testing, context (and family!) are vital



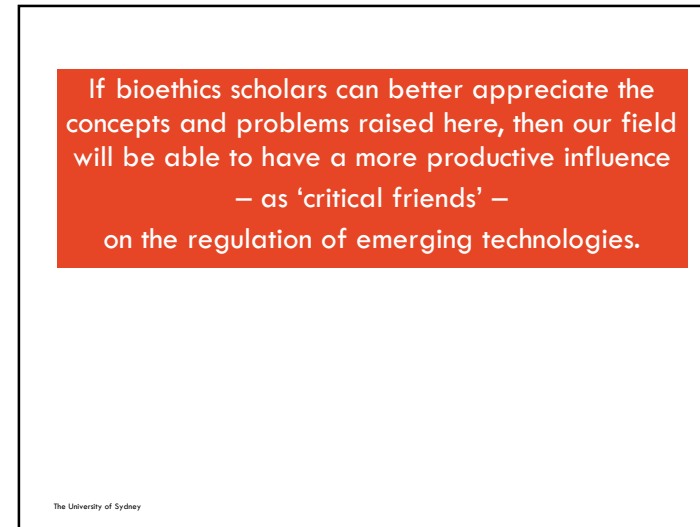
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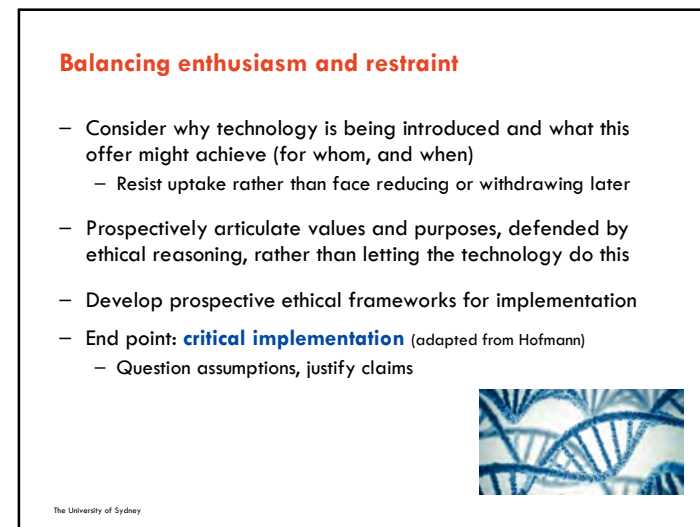
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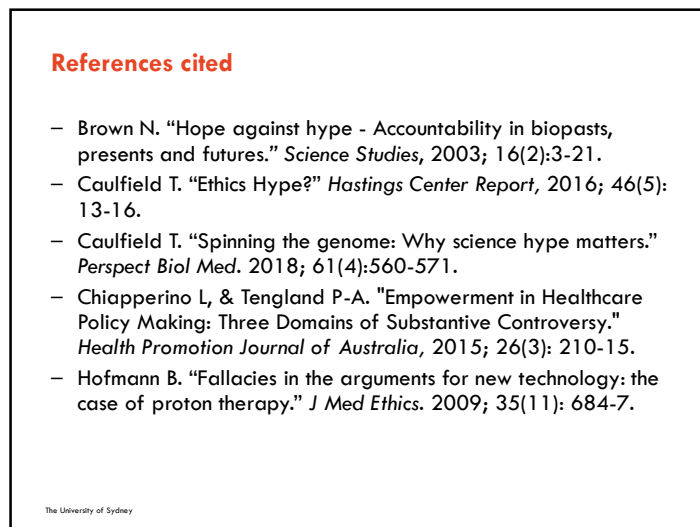
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