Knowledge
We’ve been talking today about truth (those of us who are uncomfortable with grand notions of truth might like to substitute ‘reliable knowledge’ here) and specifically in the contexts of medicine and clinical ethics. In those areas we rely on knowledge, and we rely on it being accurate knowledge (that is, true) in order to our respective jobs. Clinicians and ethicists alike need to believe that their clinical or ethical judgements are based on full, accurate information, and on a reasonable knowledge of the situations/lives (of patients or potential patients) we are looking at – something of the truth about those people and situations.

But there is a problem. **Knowledge isn’t innocent.** Work in epistemology, especially feminist epistemology and critical race studies, over the last couple of decades has identified serious structural problems in the way that knowledge is produced and shared. What’s been recognised that what we can call the **epistemic resources** available to members of a society (the collective pool of ‘things we know’) are generated and maintained within existing structures of power, authority and domination. Social and material power equates to epistemic power, that is some people having more voice than others, because they also possess the authority to decide for example which accounts to receive, from whom, in what form, which reports are legitimate and credible, how those ‘true’ accounts are fed into public discourse or policy decisions, and so on. Having this authority exerts a disproportional influence on the **collectively available resources** that enable people to make sense of their world and lives.

**This means that dominant groups in society enjoy epistemic privilege:** their forms of knowledge (their ideas about truth) are preferentially absorbed into the
background knowledge of a society. But social, political, economic forces ensure that some other kinds of knowledge are excluded from the collective resource. **Epistemic exclusion** is the opposite of epistemic privilege – it’s what happens when the accounts of particular groups of people are discounted as trivial, meaningless, uninteresting, unworthy, biased, marginal etc etc. Importantly, this is not just about a group that has a minority status, but about having a **disvalued status**.

So in a clinical context, there is a knowledge and expertise differential that comes about bcs in a very real sense, physicians know more about medicine. There is nothing unjust about this.

But on top of that people suffer what Fricker calls a ‘credibility deficit’ not just because of the power differential between physicians and patients, but because of their membership of marginalized groups and the stereotypes associated with those groups. These groups include women (see eg Foreman 2014, wrt women’s pain), black and minority ethnic people (goya 2015, Pletcher).

For example, there are many more published autobiographies and biographies of elite sportsmen and women than there are of people living with Duchenne muscular dystrophy. Both of these are minority experiences, but knowledge of what it is like to be an Olympian is more readily available to the rest of us, even though there are many more people in the world with DMD than there are elite athletes.

Epistemic exclusion makes people vulnerable to distinct though closely interlinked forms of injustice. As first characterized by Miranda Fricker, **testimonial injustice** is what happens when prejudice against a group results in its members being given less credibility than they would otherwise have (Fricker 2007, 158). Something about that marginalized group means that whatever they say is afforded less credibility than if it were said by a member of a more trusted group. [Miss Triggs]

Testimonial injustice is commonplace in the interactions between disabled and nondisabled people. Moreover, it is often an **undifferentiated response** to disabled people, irrespective of the nature of the impairment or whether it is something like a learning disability that could potentially compromise (in some ways) epistemic capacity. One example of such systematic epistemic exclusion is provided
by the so-called *central disability paradox* or *adaptive preferences*. There is compelling evidence that beliefs about quality of life with disability differ markedly between disabled and nondisabled people. Disabled people subjectively report a QOL only slightly less than, or even the same as, that reported by non-disabled people, and much higher than that *imagined* by non-disabled people (Amundsen 2005, 103).

When this difference is noticed, it is very rare for the nondisabled observer to acknowledge that disabled people might in fact be best placed to know how satisfactory their own lives are. Their claims are dismissed usually as either reflecting the limited perspective of a limited life, or a psychological defence mechanism. (She would say that, wouldn’t she?) This is *classic testimonial epistemic exclusion*: disabled people’s knowledge is dismissed because, as members of a marginalized and subordinate social group, it is assumed that their claims are inherently untrustworthy and possibly self-serving, in a way that those of nondisabled people are not.

Here’s a concrete example: people with hearing loss who use a hearing aid can, in principle, make use of induction loops in public buildings such as theatres or cinemas, that couple sound from a microphone direct to the aid, cutting out background noise. Even when installed, however, induction loops frequently stop working properly because they are inadequately maintained. Deaf people share the experience of complaining about a non-functioning induction loop, only to be told that the loop is definitely installed, is definitely switched on, is definitely working (so the fault must lie in the person’s own hearing aid: have you checked that it’s switched on), and so on. There is systematic disbelief that someone who has probably been using induction loops for decades knows what they are talking about; there may even be suspicion that the complaint is being made for other reasons, to get compensatory tickets from the cinema, for example. The lives of disabled people are full of similar stories of the denial of epistemic authority, and its consequences.

It’s important to be clear that about the kind of dismissal I’m talking about here. It is not that clinicians or ethicists disbelieve the brute facts they are told by patients or disabled clients; it’s not that they are sceptical of the facts they are being told (that they think patients are lying), but that they dispute the meaning or
interpretation given by the patient (i.e. that they don’t know what they’re talking about).

Now up to a point, it’s appropriate to take a critical approach to statements that run counter to our own everyday intuitions about what is likely to be true or not – like evaluations of post-injury quality of life. But when the evidence is as consistent as these and other data indicate, it’s worth considering what else might be going on.

This kind of epistemic exclusion is an injustice to the person concerned, because to reject someone’s knowledge is to devalue them “in [their] capacity as a knower”, as Fricker puts it, and that capacity is actually something that we consider an essential part of human personhood: **to be able to tell the truth of your life.** People encountering testimonial injustice are being challenged in their status as human persons of equal value.

Epistemic exclusion has also been identified as contributing to **hermeneutical injustice.** The epistemic tools available to make sense of the world are not a personalized interior resource, but rather are collectively generated. A society’s shared knowledge reflects the combination of perspectives of different social groups, but relations of unequal power generally skew shared epistemic resources. Socially powerful groups therefore not only get to be the ones whose knowledge is taken seriously; they are also the ones who have accurate interpretations of their experience readily available. Conversely the marginalization of disabled and other disvalued people leads to the neglect or even active suppression of the concepts, vocabulary, narratives and so on that are particularly salient to their lives.

Life as a wheelchair user, for example, generates very particular bits of knowledge, ranging from technical data about types of wheelchair, through financial information about relative costs of chairs, repairs, and funding sources, to social nous about how pedestrians and drivers respond to wheelchairs in public, to **embodied knowledge** about handling the chair through different types of space, and on and on.

If a wheelchair user’s knowledge is not considered worth including in the collective resource, that’s one problem, testimonial injustice; but that other wheelchair users are thereby barred from using it, is hermeneutical injustice. An
epistemic wrong is done to people who lack access to knowledge that helps make sense (to themselves) of their world.

But in addition to the individual disabled people affected, epistemic exclusion also involves damage done to the dominant community through this limitation on its capacity for empathy. Not to have as complete information as possible of disabled and other marginalised experience means that the collective epistemic resources are impoverished. They are structurally distorted, because it means that both popular and professional understandings of disability are disproportionately shaped by the perceptions of another, more socially and epistemically powerful group (in this case, nondisabled people). This is a harm: the wider community’s epistemic resources could be richer, more accurate, more comprehensive than they are. It’s also a harm to relevant professional groups who rely on that knowledge, such as health care professionals and clinical ethicists.

But it’s an avoidable harm because it is what Gayle Pohlaus calls wilful hermeneutical ignorance. The dominant listeners do have the option of recognising, or suspecting, their epistemic limitations and acting accordingly. If instead they refuse to engage with marginalized groups’ accounts, they maintain the harm being done.

Disability is distinctive
The theories of epistemic exclusion, suppression, injustice and so on were based primarily on exemplar cases of social stratification by gender and race, sometimes gender identity or sexual orientation. However, there are some features of disability and often ill-health as well, that distinguish it from these other social ontologies, and create additional obstacles to knowledge.

Chief among these is the fact that disability entails differences in body form or function, and this raises the issue of embodiment and embodied knowledge. I do not have time to argue this fully here, but note that there is some evidence that our embodiment influences not just the experiences we can undergo, for both biological and social reasons; but more fundamentally also the perceptions, interpretations, meanings, priorities, preferences and so on associated with those experiences. If so then having a variant or anomalous embodiment is likely to
introduce relevant epistemic differences that will be difficult or impossible to convey through description. Experiences such as the fatigue of ME or chronic illness, or what it is like learning how to mobilise a prosthetic limb, are so quintessentially embodied as to be hard if not impossible to communicate any useful sense of ‘what it is like’ in order to increase others’ knowledge and understanding.

A classic example of the way in which anomalous embodiment can generate a perspective that is not intuitively obvious to others is that of [so-called ‘choosing D/deaf babies’]. Back in 2002, a genetically deaf lesbian couple in Washington DC hit the headlines because they wanted to have a child, via donor insemination, but wanted to increase the chances of having a deaf child by using a sperm donor also with genetic deafness (and found that most commercial sperm banks don’t use donors with known genetic ‘defects’). When it became public, this now notorious [and to be honest heavily over-worked in bioethics] case generated a massive amount of public and professional debate. More detail can be found elsewhere, but the point I want to make here is that for these women, and others who have expressed a similar preference, their embodied and socially embedded knowledge (of the signing Deaf world and so on) made this preference obvious and morally unproblematic. By contrast the majority group (that is most hearing people) found it disturbing and inexplicable. Because only limited knowledge of the lives of culturally Deaf people held within the collective epistemic resources; the embodied and socially embedded knowledge behind the preference for a child was unknown to most people and not readily conveyed through language or imagery, so for most hearing people it was impossible to say ‘I know what that life is like and I understand that choice’.

**Why this is important for disabled people and disability**

As a bioethicist with an interest in disability, I became involved in this field because of bioethics’ role in evaluating the moral permissibility of literally life or death medical interventions around disabling conditions: prenatal selection, neonatal care, decisions about assisted suicide, and so on. An essential part of these judgements is assessing the quality of life of the affected person (or future person). I have questioned the notion that accurate third party judgements of QOL can always be
made, if the life involves a significantly different kind of human functioning from the norm. I argue that this is because estimating QOL means having some sense of what it is like to be in that position, to live that life, to find that life to be a flourishing one or not. The question that is introduced by a more skeptical approach to the ways in which epistemic power interweaves with social and material power, is whether our judgements about the moral permissibility of interventions in to life and death, are distorted by an epistemic deficit when it comes to people in very different bodies, which in turn limits our capacity to make accurate predictions about life and flourishing?

**Suggestions for the future**

Bearing in mind the arguments I’ve been putting forward, here are a couple of suggestions of how to improve things.

**A more critical clinical epistemology.** A critical epistemology starts by disbelieving the assumption that epistemic authority or access to epistemic resources is neutral or fairly distributed (is transparently true). It encourages us to examine in detail the precise processes and patterns of dominance and marginalization and silencing that enable the perspectives of some people to override those of others, eg here of nondisabled people to override those of disabled people, or of particular types of impairment over other types (Walker 2002, 60). By identifying both the substantive gaps and the mechanics of epistemic exclusion, it points us towards the ways these can be remedied.

**Revised and expanded epistemic resources.** A first step is acknowledging that the collective epistemic resources (which are also the ones that HCP and ethicists draw on) are inadequate. A second is to acknowledge that ignorance about disabled lives is not an inevitability, but something we can choose to improve. So not just adopting a critical standpoint, but also making a conscious and concerted effort to reform the instituted social imaginaries of the norms of embodiment. In the context of disability, strategies might include ensuring access to education, communications and assistive devices that enable people with a range of impairments to contribute
and find knowledge; effective representation by disabled people on the sorts of bodies that influence healthcare or social policy; efforts by media to present the narratives of disabled people’s lives and experiences beyond mainstream stereotyping, and so on.

But changing our epistemological resources and approaches is far from easy. Epistemological frameworks are highly resilient (Dotson 2014) because they function very well for the dominant community (of nondisabled people in this case), and are perpetuated along with very persistent networks of social privilege and power. As feminist critique has pointed out, such frameworks also work to hide the fact that only the aspects of the world experienced from a dominant position make it to any prominence in the collective resources. Even obvious epistemic gaps about disability, then, will persist indefinitely.

Moreover, there is always an engrained cultural resistance to engaging with marginal knowledge. Much of this comes from not just the political but also the psychic consequences of recognising one’s own epistemic privilege; realizing that one is benefiting from systemic, ingrained epistemic exclusion generates a sense of guilt and powerlessness that is counterproductive to empathic engagement. There is also emotional resistance to feeling the pain of people in situations of oppression.

But I would also say that there are unique blocks to acquiring the knowledge about disabled people’s lives that are not the same as the blocks against knowledge of the lived experience of women, say, or BAME. (Note I’m not claiming that there are no blocks here, just that there is something distinctive about disability.) These stem fundamentally from a profound cultural ambivalence, even hostility, towards anomalous bodies. While in many respects today’s cultural climate is increasingly more positive to diversity, reflected in anti-discrimination laws and so on, attitudes to disability (and therefore to disabled people) I would argue remain strongly negative.

So developing a greater acceptance of the normality of anomalous embodiment and disability is a prerequisite for incorporating disabled knowledge into the collective epistemic resources, and allowing that to inform what we can reasonably claim to be true about disabled lives.