Identity and information – learning from genetics, looking beyond genetics

1. **Thank you – Mason Institute – hope we host them back in real life soon**
2. **Background**
   - I am going to be talking today about a question that I've been working on in various forms for a while
     - …In what ways might information about our bodies, biology and health – particularly that which is not directly available to us, that is generated by biotechnologies or analysis of big data – be relevant, even critical, to our identities as individual persons and our associated needs and interests?
     - Particularly can we understand this significance without recourse to reductive or essentialised views of who we are?
   - Where I am coming from
     - bioethics with roots in philosophical analysis of concepts and values
     - but … also working in a Law School so always conscious of the practical and regulatory implications of the ethical arguments I deal with + of the necessity to stay rooted in evidence what actually matters to people… which is one of the reasons why it such a privilege to be able to join these meetings of the Genethics Forum
   - Why am I talking about this topic to you?
     - Because I suspect that the ideas of identity significance that I draw upon may be more familiar to you that people working in a lot of other fields of healthcare and
     - Because the implications of what I have to say extend far beyond genetics and genomics and – if this is so – then there are many contexts I which we need to learn lessons from *clinical geneticists, genetic counsellors, and genetic nurses* about when and how to support people through experiences that could have marked – and ethically significant impacts on their identities.
3. **Identity impacts introduced**
   - I want to start by briefly saying a little more about what I mean by identity in this context.
   - Here I am referring to identity in terms of 'who we are as individuals', as related to our personalities and as the source of our choices, judgements, outlook and values
     - So, not just the drier sense of *numerical* identification – which is concerned with matching *things* with *people* – for example as applies when bio-information is used in forensics or biometric id cards - or that is the concern of data protection law
     - Nor am I talking about the other sense of identity on this slide
     - Although, there may be some intersections between ethical concerns raised by these two kinds of identity it's the former I am focusing on here
   - In context of this 'characterisation' sense of identity then, we may be familiar with the idea that health-related or genetic information might be used – or *ab*used – by *other* people to make judgements about our who we are and what we are like
     - But what is – perhaps – less widely discussed are
       - the impacts of our *own* encounters with these kinds of information on our own self-conceptions
       - and the personal and, more particularly, the *ethical* significance of these impacts
       - and from there – the question of how potential identity-related impacts of information should inform practices, policies and rules governing when and how we access this information?

- I say these impacts our own encounters with information about us are "less widely discussed", but I am conscious here that I am talking to a gathering of genetic health professionals – and that your work means you are likely to be abundantly aware of the ways that genetic information can have personal, not just clinical significance, for those it relates to
- So let me take a step back here, and reflect on what the *academic* debate about the relationship between identity and bioinformation looks like.
- Here there is – inarguably – recognition that – for example – test results for genetic susceptibility to disease can – as a matter of empirical fact – affect how people see themselves. For example leading them to
    - To adopt 'illness' or 'risk identities'
        - Either in terms of how they describe themselves
        - Or in more practical or activist ways
    - To feel more connected to, or separate from, others depending on whether or not they share a risk status
    - Or to feel differently about their bodies, their strengths and vulnerabilities
- But what there is less agreement about is whether *and why* these kinds of impacts might be a *good* or a *bad* thing for our identities and our wellbeing, and whether they are a proper topic for serious *ethical* attention
- More specifically, arguments about this are often deeply polarised

4. Polarisation

- What I mean by this is that they are polarised between
    - On one, hand, the view that information about our biological selves is really important – even vital – to our identities and self-understanding, that it provides authoritative, objective, corrective or 'true' insights into who we 'really' are
        - For example, this kind of position is familiar from debates about the importance of people conceived using donor gametes being told about their origins – and it is a position that has taken hold in UK policy and – for example – in the European Court of Human Rights
        - In a very different context, similar views are sometimes expressed in relation to data generated by health-tracking 'wearables' – for example that information about our sleep patterns or heartrate – about 'the quantified self' – allows us to better understand who we are.
    - On the other hand there is the contrary view – which is perhaps more commonly encountered in the ethics literature – that
        - *at best*, knowledge of our genetic origins, health risks, or sleep patterns are irrelevant to our identities
        - *but at worst* it is both false and damaging to suggest that this kind of knowledge is important
            - because it implies a restrictive, reductive and bioessentialised view of the self
                - which we unearth rather than create
                - that we cannot escape our biology
                - in the context of genetic origins, for example, it is argued that emphasising the importance of genetic ties devalues the importance of chosen families and

the role of our environments and social relationships in shaping who we are
        - In the contexts of health wearables, meanwhile, it is argued that quantified 'scientistic' data get in the way of our more authentic and useful direct encounters with our own embodied experiences and senses
    - Well we might think 'so what?' It's all very well for academic ethicists to disagree about these things
    - But this polarised debate doesn't help policy-makers, technology developers, or healthcare professionals think about when disclosure of information to those to whom it pertains might be permissible, required or problematic *if it does look like it might have identity impacts*.
        - We need conceptual and evaluative tools to understand when and why identity interests in accessing information – or not – might be engaged.

5. My intuition

- And beyond this practical concern - neither extreme of this polarised argument seem quite to capture what is at stake here.
    - We can, absolutely, recognise that its implausible that who we are is determined by our bodies, biology or genes
        - That this not only misrepresent the science
        - But is also open to ready counterexamples in the form of people who happily resist being defined by their health or bodies
    - But there remains the fact that various aspects of our bodies and biology do shape, enable and limit many aspects of our lives, our engagement with the world and others people
        - Our senses and cognition are inescapably embodied
        - Chronic disease does often affect the way we experience the world
        - And our sex, age, skin colour and physical abilities shape – for better or worse – how we navigate it and describe ourselves
        - And there *are* people who say that, for example, knowing about their genetic parentage is important to their sense of who they are;
    - Should we regard these experiences and attitudes as a gravely misplaced?
    - My intuition is that we should not

6. My argument

- My research seeks to fill out this underlying intuition
- In doing so I appeal to a conception of identity (which may be familiar to many of you) according to which that our identities are constituted by self-constructed, narratives about who we are and what we are like.
    - These are **narratives** within which our characteristics, experiences, behaviours, values and commitments, past, present and future exist in relationships of mutual shaping and explicability – making them meaningful and intelligible to us and to those around us.
    - And we're talking here about identity in the sense of ***practical*** *self-characterisation* – 'what I am like and informs my perspective on the world and what motives me' –
- According to the narrative account of identity - we create our identities in this characterisation sense, through the interpretive and (to some degree) selective accounts we give – or would in principle give – of what we are like.
- But we can't just tell any old stories as the whim takes us.
    - **Basic**: This is because our identity narratives aren't just a bit of window dressing

        - (on this view) They *constitute* who we are
        - they are the source for our evaluative and practical engagement with and navigation of the world
        - they provide the frameworks for our judgements and reasons for our choices and actions, and bases of our commitments and projects
        - and as such they need to make sense to us and provide a reasonably coherent foundations for these undertakings
    - **Social**: We also need to function socially, so our defining narratives have to make some kind of sense to, and be recognisable to, those around us – indeed narrative accounts emphasise the discursive, relational and socially embedded nature of identity construction
    - **Embodied**: But more than this – and this is an element that is sometimes missed in some prominent narrative accounts of identity – our identities also need to make sense to us in the context of and help us to navigate our embodied lives, experiences and traits, and the scope and limits these place on self-creation.
- **This is where information about our health, biology and bodies – including, but not limited to genetic information, comes in**
    - My suggestion is that this information can provide us with potentially valuable insights, perspectives, and interpretive tools that we can use in our ongoing construction and refinement of inhabitable, coherent and intelligible identity narratives

Examples

- *What are some possible examples of bio-information fulfilling these kinds of roles – these are examples from the social science literature…*
    - Neuroimaging findings indicating abnormal neural functioning associated by bipolar disorder might help someone to make sense of their recent experiences and understand that they are [quoting here] "not just crazy"
    - Testing positive for BRCA1 or 2 mutations might lead someone to reflect on what matters to them and their relationships to their family and community
    - Alerts generated by a neural implant warning the user of an epileptic seizure could provide opportunity for the user to take medication, avert the seizure and benefit from the increased independence and control over their lives [quoting one participant in an Australian 'first in human' study] "with this device I found myself"
    - Learning of their donor conception might help someone make sense of dynamics in the relationships within their family
- Importantly, these reactions do not necessarily depend on the clinical actionability of the information – they do not necessarily relate to specific healthcare choices, behaviour changes or practical decisions –I'd suggest that they are about constructing and making sense of the story of who one is … of one's identity

Bringing the argument home [READ]

- My more strongly normative suggestion is then that - the narrative edits facilitated by these kinds of information aren't just morally neutral qualitative changes, or 'interesting or nice to have' details
- We each have – I suggest – significant interests in developing inhabitable, coherent and intelligible and personally meaningful self-narratives, because of the irreducible role a narrative exhibiting these features plays in:
    - allowing us to understand who we are
    - supporting our capacities to make considered evaluations and act from these

    - and supplying a reasonably stable (or rather, explicably evolving) foundation upon which to base long-term commitments, projects and relationships.
    - And thus in underpinning some of the key conditions of a full and flourishing life:
- **PAYOFF** So my further suggestion is that *when* – and to the *extent* that – information about our health, bodies and biology contributes to – or detracts from – our abilities to
    - develop self-narratives that *are* and *remain* inhabitable, meaningful, coherent and intelligible when confronted by the vagaries of embodied, relational lives
    - that support us in interpreting and contextualising our embodied traits and experiences, understanding or anticipating how our health, our physical capabilities and vulnerabilities, and our cognitive or affective states might contribute to, shape or disrupt our sense of who we are
    - that help us to navigate a world in which our bodies mediate our experiences…
    - … we have non-trivial interests in whether and how we are able to access this information
    - It is a potentially valuable – instrumental not essential – tool of practical identity construction
- With two important caveats:
    - These kinds of information will always be welcome or valuable…
        - For example, a mental health diagnosis that introduces a stigmatising self-descriptor
        - A test result that threatens a source of meaning (for example, an inherited cancer risk that throws a new light on plans for parenthood)
        - or false or unreliable information that misleads us as to what our symptoms mean or what our future may hold
    - And whether information is valuable, detrimental or irrelevant to someone's self-narrative will come down to our own individual needs and the narratives we already have, and the contexts in which it is encountered

7. Implications of this – breathe, key change

- To this audience this much theory may seem unnecessary
    - You don't need a specifically – and prescriptively – narrative conception of identity in order to know that information about risk of inherited disease or carrier status often matters to your patients – in beneficial or distressing ways – for reasons that extend beyond its immediate clinical value
- But what – I hope - it might help to do is point to the importance of paying attention to potential identity impacts
    - beyond the clinic
    - beyond information that which conveys clinically actionable or strongly predictive insights
    - and, indeed, well beyond genetic information
- And, by emphasising the instrumental, interpretive, story-telling roles of bio-information, the account that I have outlined, offers a way of making sense of this importance that does not need to make any ill-founded or troubling appeals to being defined and determined by our bodies, let alone our genes.

8. In what kind of contexts might these propositions make a difference?

- Well, first we might look to contexts in which information is not be routinely disclosed, but identity-related interests might give us further reasons to do so
- For example -

    - The return of individual findings from health-related research – whether these are planned, incidental or secondary findings. Currently, guidance and consensus statements on policies for return of findings tend (quite appropriately) to emphasise clinical actionability, with only some hints that participants might have a wider range of reasons to value findings.
    - Or, consider the recent decision of the UK High Court that healthcare professionals have a *legal* duty to conduct a balancing exercise between maintaining patient confidentiality on one hand and disclosing information to others with whom they have a close professional relationship if this could avert a significant risk of serious harm. What might count as serious harm under this new duty remains to be seen. The instant case indicates that it could extend beyond health threats, to include the opportunity to make reproductive decisions. We might then ask whether it could – and should – also include some kind of identity harms (which might themselves include reproductive decision-making) as well as those of having one's existing self-descriptors and life projects fractured by unforeseen illness or undiagnosed symptoms, in ways that could be avoided if information was shared.
- Meanwhile, on the other side of the coin, we have contexts in which information may be relatively readily available – for example in consumer contexts – but attention to potential identity impacts might lead us to question whether that should always be the case
- For example,
    - information generated by online genetic 'ancestry tracing' services
    - data displayed by wearables devices about our sleep patterns or concentration levels
    - or wellbeing advice offered on social media, triggered by what algorithmic analyses of our online behaviours about our mental health – so called 'digital phenotyping'…
- …Are these kinds of information simply innocuous – because they aren't likely to be clinically significant and could satisfy 'curiosity' – or should we be thinking harder about whether they could nevertheless have non-trivial negative impacts on our own accounts of who we are – I'm thinking here particularly about instances when they are misleading or opaque.
- My suggestion is that at either end of this spectrum -where disclosure is uncommon *or* where it is unquestioned - potential identity impacts deserve serious ethical attention
    - Attention alongside more familiar concerns with clinical utility, privacy or autonomy
    - And attention that informs disclosure practices and policies
        - And not just policies about *whether* it should be disclosed, but also how *how*.

9. What then can we learn from clinical genetics?

- Why raise the potential identity-significance of non-genetic information and information transactions beyond the clinic to a gathering of genetic health practitioners?
- I would suggest that – if other areas of medicine, health research and technology design are going to governing information disclosures in ways that respond to potential identity interests, then they have *a great deal to learn* from those who work in clinical genetics and genetic counselling …given long experiences in these fields of anticipating and navigating impacts of information disclosures that have potentially wide personal and relational ramifications.
    - At the most fundamental level, this includes drawing upon the sheer depth of knowledge in clinical genetics of how people react to novel and complex information – how do they use it, what do they tend to value or regret about knowing or not knowing?

- Then – moving beyond the bald question of *whether* to disclose to thinking about the significance of *how* information is conveyed…
    - Given the idiosyncrasy and hence unpredictability of identity I pacts ….there are valuable lessons about how its existence can be raised and the opportunity to find out more be offered, without pre-empting disclosure or incurring precisely the harms one wishes to avoid?
    - And, about how one can support the interpretation and comprehension of complex or uncertain of findings and help recipients to understand what these *cannot* tell them, just as much as what they *can* – this is particularly important given the particular harms that could arise from building one's self-conception around false, misleading or misinterpreted information.
    - Our own self-narratives inevitably intersect with those of the people with whom we share our lives – giving rise to shared interests in the kinds of stories we tell and the tools we use to do so – and here we can learn from clinical genetics established experience of moving away from individualistic models of control and ethical concern, and navigating intersecting and competing informational interests
    - And finally … perhaps most importantly ...given that narrative identity construction is a necessarily interpretive, discursive and relational – involving (in Alasdair McIntyre's words) the "giving and receiving of accounts" of who we are – the principles of non-directiveness coupled with interpretive support – that are intrinsic to genetic counselling would have a critical role to play in disclosure practices that support the shared process of meaning-making that is involved in integrating – or indeed rejecting – new bio-information from our sef-narratives.

Just before I close – it's worth noting that I've focused here on the potential effects of information on our identity narratives. But of course it is not only information that changes our sense of who we are but also the ways that medicine and biotechnologies change our bodies themselves and our relationships to them that require our attention. For example, … when I was part of drawing up recommendations from the Nuffield Council on Bioethics that called for a process analogous to genetic counselling to be part of preparing those undergoing deep brain stimulation for the potential for this neural intervention to have profound effects on people's experiences and behaviours.

Whether it informational transactions or the direct effects of devices, my underlying suggestion here is that when we think in terms of our identities as things we create rather than just have, things that can serve us better or less well, and rather than static entities that can only be presented or lost, instead the result of perpetual interpretive engaging with our experiences and the world around us… then we can understand the ways that many aspects of health, healthcare and medicine may provide the tools for or obstacles to intelligible and inhabitable identity construction – and clinical genetics has much to teach us about how we can be supported in using these tools for better rather than worse.