

**SEMINAR 4: Comparing forensic and medical genetic technologies**

**Outcomes of the meeting: identifying a research agenda**

**The goals of this seminar:**

- The focus of this 4<sup>th</sup> seminar was on comparing the scope, uses and governance of genetic technologies in biomedical/clinical and forensic settings.
- Whilst many jurisdictions currently ban routine exchange of information between ‘criminal’ and ‘medical’ genetic databases, emerging technological innovations in genetic profiling blur the line between forensic and medical information.
- This seminar discussed:
  - the differences and similarities in the uses and governance of such technologies across the two domains;
  - the challenges that might arise from the multiple uses that can be made of genetic information,
  - and the responsibilities that rest with the different stakeholders in acting as collectors and providers of, and guardians for, such information.
- The speakers were: (alphabetical order)
  - Niels Morling (Department of Forensic Medicine, University of Copenhagen): *‘Forensic genetics: ethical considerations’*
  - Bronwyn Parry (Department of Global Health & Social Medicine, King’s College London): *‘Legitimizing ‘spaces of exception’ for data exchange: family reunification, trafficking and the war on terror’*
  - Barbara Prainsack (Department of Global Health & Social Medicine, King’s College London): *‘The datafication of everything? Effects of convergence of forensic and medical bioinformation’*
  - Gethin Rees (School of Geography, Politics and Sociology, Newcastle University): *‘The ‘second victimisation’: forensic medical practitioners’ attitudes to standardisation in forensic evidence collection’*
  - Simon Woods (Policy, Ethics and Life Sciences Research Centre, Newcastle University) : *‘Framing common goods: from genomics to forensic ‘big data’ ‘*
- This seminar illustrates our broader interests in connecting forensic science studies to other, related, areas to see if, and how they are, or should be, connected, compared and contrasted. An important area for such consideration is that of genetic technologies in health studies.
- Mutual learning and the sharing of knowledge across different areas assists the anticipation of challenging issues that might arise from the increasing overlaps between the two areas.
- These discussions have been taking place in various international fora for the last 15 years or so, and an interesting body of literature has gradually been building up, not least pieces written by colleagues participating in this seminar series, and their colleagues in other networks, but the gains from such comparative exercises remains under-exploited.
- That literature, and the papers presented at this fourth seminar, suggest that there is much need, and ample opportunity, for further research. This document, arising out of the presentations and discussions at this seminar, seeks to identify the opportunities, gaps & themes for further research.

- We suggest five overlapping lines of inquiry in which the deployment of genetic technologies in forensic and biomedical contexts might be explored further.

**(i) EXPLORING THE SOCIO-CULTURAL POSITIONINGS OF KEY ELEMENTS THAT UNDERPIN THESE AREAS OF WORK, e.g.**

- **Bodies and embodiment:**
  - What is the history of, and current trends in, the characterisation of bodies and DNA in the health field and the forensic field?
  - How is materiality ascribed to this central aspect in each field and what are the impacts of those varying ascriptions?
- **Institutional identities:**
  - What is the cultural positioning of the key institutions that promote, organise, and articulate the goals of forensics or clinical work?
  - What is seen by various publics and other stakeholders as the relevant umbrella or 'front' institution, e.g. the NHS, the police force? These are not strictly correct in either case but if those are the public institutional identity for these two areas of work, what are the knock-on effects?
  - What are the notions of acceptability and respectability associated with those institutions, rightly or wrongly, and how does this vary across societies? E.g. in the UK, how does the image of the NHS compare to that of the police force; what effects does that have? How does that play out in other societies? For example, Garcia-Deister and Lopez-Beltran (2015) discuss the parallel workings of these two sets of institutions in Mexico; but the relationship between the two institutions is not the same in the USA or the UK, so how does that relationship play out in different societies and across different time periods?
  - How does the focus on *genetic* technologies play into established relationships between medicine and forensic activities, such as pathology?
  - How do these various institutional and epistemic cultures interplay, or clash, with other institutions e.g. medicine, forensics and kinship? Or medicine, forensics and law? (Jasanoff, 2006; Haimes, 2006; Haimes & Toom, 2014)
- **Professional identities across both contexts:**
  - Who are the relevant professionals and other practitioners to consider in each domain?
  - How have their professional identities developed and changed over time?
  - How is each professional grouping changed by the intersection of their various responsibilities and working practices? The presentation by Gethin Rees illustrated one set of intersections; what are the other relevant examples?
- How are those professional groupings depicted e.g. in popular culture?
- **The very notion of the 'investigation':**
  - What does this mean across the two contexts?
  - This is a phrase that is taken for granted in both fields and yet the processes and purposes of 'the investigation' are very different: we use the same phrases to describe what we are doing as social researchers, clinical researchers and as criminal investigators but with very different consequences.

- It would be useful to unpack that term of ‘investigation’, both conceptually and empirically to see how everyday practices compare and contrast.
- ‘Investigation’ is better understood as a socio-technical intervention, recognising that it is not just a passive observation of external events and acknowledging that the nature of that intervention can be very different in different epistemic cultures, including clinical and forensic science. After all, contributing samples to Biobank UK is very different to ‘helping police with their inquiries’! And yet what happens if one becomes the other: if a request is made to use samples provided for medical research to assist criminal investigations? (See below)

That takes us on to the second area that would benefit from further exploration:

**(ii) AREAS OF INTERFACE AND OVERLAP IN THE WORLDS OF PRACTICE:**

- There is a need to consider these overlaps at multiple levels at the same time
- Clearly there are issues of overlap and dual use in the area of ‘big data’ and ‘datafication’ as Barbara Prainsack’s presentation so clearly demonstrated.
- Police access to clinical genetics databases is one area that has been frequently mentioned though not discussed in depth, as far as we know:
  - Have any cases arisen in the UK where the police have requested access to health genetic biobanks to assist their inquiries? (Very clear that for BioBankUK at least police would need a court order and BBUK say they will strongly oppose any court order that requires them to make the database open to the police);
  - What is the situation with other major UK genetics and health databases such as the 100,000 Genomes Project?
  - What is the situation in other countries?
  - What is the reasoning that lies behind each position?
- **And there are other specifically situated practices that would benefit from further investigation and granular, detailed analyses:** for example,
  - police requests for access to what are often thought of as ‘routine’, ‘mundane’, ‘non-problematic’ records e.g. dental records, for identification purposes;
  - other requests by police forces to use the medical records that contain genetic information or materials specifically of close relatives, to assist identification of a known suspect (e.g. the 2004/5 Dennis Rader case in Wichita, USA);
  - the uses of familial searching to assist identification in criminal investigations and the impact that that has on other matters of genetic relatedness (Haimes, 2006);
  - What if a criminal investigation reveals other matters of genetic relatedness; should they tell the individuals involved? This situation is subject to ongoing debates in the clinical setting (e.g. Lucassen and Parker, 2001) but what are the established practices in the forensic field, and what are the reasons for this?

- the Child Support Agency's use of paternity testing to establish financial responsibility for a child (Lowerson, 2000) indicated that these are matters for civil law as well as criminal law
- What are the concerns, both practical and in principle, when health data and criminal justice data ( as well as data on housing, social services, education etc) are linked or even aggregated, as proposed in the context of the Learning Health System?
- **Global perspectives** need to be considered too:
  - E.g. what occurs in emergency situations where there are mass deaths (e.g. in the context of trying to identify victims in large scale disasters)? As Nils Morling pointed out in his presentation, in those situations, relatives and others might want to promote the use of existing medical records to help with forensic identification processes.
- **State-sponsored investigations?**
  - Another overlap could occur through the ways in which governments might legitimate research at the forensic and health interfaces
  - E.g. work on 'the criminal gene', or work on the idea of ethnicity and crime (Murphy, 2016:367), or on the 'violence gene' (ibid; Levitt and Manson, 2007))
  - There could be political pressure on researchers to look at these alleged associations, without the fundamental terms being delineated or argued through.
- **Therefore, in brief:**
  - That interface between crime and health, and between forensic and health genetic information, can play out in a number of different ways (it's not just a case of access to genetic *databases*; access to wider holdings of genetic information can be thought to be equally useful in certain circumstances); it's not always obvious what the interface or overlap will be.
  - And it might not be inherently 'bad' for that overlap to occur; while there might be reasons to resist overlaps in some circumstances (Murphy, 2016), in other situations relatives / families might advocate such uses. So these are not just straightforward issues of civil rights or civil liberties.
  - Nonetheless, as Bronwyn Parry argued in her presentation, it is vital to be wary of 'legitimising exceptionality'. State agencies might argue that it is legitimate to access and use data provided for one purpose (e.g. to assist health research) for other purposes, because of the exceptional circumstances pertaining (e.g. detecting terrorists; identifying abducted children; securing arrests of suspects). This presentation alerts us to the need to study the occasions where this happens, to identify and challenge the assumptions that underpin such uses and to identify the longer-term consequences of such incursions.
  - The adequate governance of data aggregation, data mining and data analysis, accompanying increasing surveillance efforts by the state, will be a growing challenge.

- **These discussions suggest a lot more questions to explore about any particular circumstance of overlap or interface:**
  - Which research agendas do these access issues play into?
  - Who has a voice in deciding those research agendas?
  - What are the circumstances in which such overlaps occur and such requests are made?
  - Should there be limits on which records are accessible and which not?
  - Who decides whether there should be access or not?
  - What standards of consent are needed?
  - And who is equipped to deal with the consequences – e.g. when identification occurs and shows misattributed parentage or examples of other criminal activities, etc; how are different agencies, institutions, professionals prepared for handling these possibilities?

**(iii) COMPARING EPISTEMIC CULTURES:**

- **This seminar revealed further opportunities to extend Knorr Cetina's (1999) classic study:** 'Epistemic Cultures: How the sciences make knowledge'
  - Knorr-Cetina defines epistemic cultures as *'those amalgams of arrangements and mechanisms – bonded through affinity, necessity and historical coincidence - which, in a given field, make up how we know what we know'* (1999:1)
  - She examines 'the construction of the machineries of knowledge construction' (1999:3).
  - Conducted studies of high energy physics and a molecular cell biology group; she alternates between the two sciences, 'highlighting the stark differences between how work is conducted and how knowledge is produced' (Markovsky, 2000:556)
  
- **Comparative analyses of the 'health' and 'forensic' epistemic cultures:**
  - **What might be done:**
    - E.g. studies of the two areas of forensic genetic technologies and health genetic technologies or even between three areas, incorporating the interplay between those two and areas of e.g. law or kinship.
  - **How to do such studies:**
    - Joint ethnographic studies of particular settings identified above and or of the everyday workings of practitioners in these fields e.g. a joint ethnography of forensic medicine laboratories and of major health initiatives such as the '100,000 Genomes Project'?
    - Note the benefits and usefulness of interdisciplinary research in such studies, as this seminar series demonstrates and as we've written about as a group elsewhere (Evison et al, 2012, encouraging a move *'from normative antagonism to interdisciplinary collaboration'*)
  
- **Indications of possible outcomes of such studies:**

- Gofton and Haines (1999) 'Necessary evils? Opening up closings in Sociology and Biotechnology', Sociological Research Online, which explored the possible overlaps and contrasts between health and food biotechnologies. This paper showed:
  - That notions of 'genetics' and all its different variations carry a range of different associations and 'cultural echoes', depending on location/context; each context draws upon different hopes and fears.
  - A comparative perspective opens up theoretical possibilities and permits new insights
  - In the health field at the time it was possible to provide a cultural mapping of actors, institutions and structures, but less so for food. What would that cultural mapping look like across the two domains of health and forensic genetic technologies?
  - Cultural construction of the two domains as sacred (medicine) and profane (food) to use Eliade's (1957/9) classic phrase - so where would forensic genetic technologies be placed in this dualism and why?
- A more recent and directly relevant study by García-Deister & López-Beltrán (2015) shows further benefits of such a study. They provide '*a comparison between genomic medicine and forensic genetics in Mexico, in light of recent depictions of the nation as a 'país de gordos' (country of the fat) and a 'país de muertos' (country of the dead).*'
  - This paper reveals a range of understandings about:
    - how genetics is differently formulated in each field,
    - as well as how the relevant publics are constructed;
    - how relationships of trust play out differently in the different fields;
    - This research has implications for understanding the specifics of citizenship and also 'bio-power'.

**(iv) SOCIOLOGICAL AND SOCIO-ETHICAL FRAMINGS WITHIN THE TWO DOMAINS:**

- **How is participation in each field characterised by socio-ethical framings?**
  - E.g. for clinical databases, considerations such as Respect / Consent / Feedback / Accountability / Consultation / Ethical research / Public ownership informed the setting up of Biobank UK (from Cragg Ross Dawson study, 2000)
- But are there assumptions that notions of 'autonomy' and 'consent' are more relevant and important in the clinical context than in criminal investigations – and, if so, is this correct?
  - In health contexts of e.g. BBUK:
    - Themes of autonomy and consent are seen as applying both to the individual and also to the societal relationship with the science (see, for example, the Ethics and Governance Framework of the Ethics and Governance Council of BBUK.
    - But how much have these considerations been duplicated/ extended in 100,000 Genomes Project?
    - And are they common tropes for justifying health biobanks elsewhere in the world? Are there other, more/less valid framings?
  - In relation to forensic databases:

- the importance of these themes appears to be very much one of community consent and approval for the establishment of a NDNAD;
- very little consideration of the individual, who is positioned as being either suspicious, or culpable (or in other negative ways)?
- (See, for example, how individuals featured in the Rader/Wichita case mentioned previously (and in Bronwyn Parry's presentation); how did consent function there? But here a case was made for exceptional access and non-consent because of a stated need not to alert the suspect)
- But actually consent issues in the forensic context are more complicated than might be assumed, since:
  - samples are taken from other categories of people, not just suspects (e.g. victims; police officers; participants in mass screenings);
  - through different means (e.g. familial searching processes; touch DNA and DNA transfer; contamination)
  - and are retained for a variety of reasons
  - and are subject to diverse governance regimes
- And in the health context, questions of consent are in fact still fiercely debated:
  - e.g. questions about open/blanket consent;
  - and also, more recently and interestingly, questions about 'hybrid' projects such as the 100,000 Genomes Project where research and therapy are entangled in a number of complex relationships, given its focus on rare diseases, as Simon Woods' presentation indicated.
- **Questions of ownership of genetic information:**
  - In forensics, there is the idea of the 'unwitting genetic witness' (Haimes, 2006), whose information is vital to the detection of suspects simply through being genetically related to a suspect; who owns that information and what responsibility do such suspects have to assist the police with their inquiries?
  - Similarly there are questions in health settings of the shared ownership of genetic information in families, in relation to feedback on risks of ill-health, contested paternity etc, as indicated by Lorraine Cowley's work in the PEALS Research Centre; what are the responsibilities of genetically related individuals to participate in such health investigations and to share knowledge amongst themselves?
  - These questions of 'ownership', and its associated responsibilities, are extended by the involvement of commercial interests in major health initiatives like the 100,000 Genomes Project, again explained in Simon Woods' presentation. How do potential participants in such initiatives view these commercial goals and interests and how does this affect their participation, and their rights as participants?
- **The non-deliberate provision of samples:**
  - Just as family members might be unknowingly implicated in forensic investigations simply through their genetic link to other individuals, others might be unknowingly implicated in other ways, for example, through 'left-behind' stains at a crime scene. How are innocent leavings-behind identified and dealt with? What are the knock-on effects of being implicated, through one's genetic profile, in such situations??
  - There are also 'left-behind' bio-samples in the health context too, given for one purpose (e.g. medical tests), that are then wanted for other studies. Who should decide whether such other uses are legitimate? What standards of consent are required here? Are these open to concerns about 'legitimising exceptionality' as

mentioned earlier, simply because it is said to be efficient to use such existing samples, while being inefficient to seek new consents for the donors?

- As Bronwyn Parry warned in her presentation, casualness about practices in one context could ‘normalise’ casualness in other contexts/settings

So, in brief, the idea of ‘helping the police with their inquiries’ and ‘helping researchers with their inquiries’ can be seen to be heavily loaded circumstances that would benefit from more detailed exploration and comparison across the two domains.

Finally,

**(v) GOVERNANCE ISSUES:**

- Comparison across the two domains facilitates a discussion about the challenges for, and nature of, governance structures within, and across, the two domains.
- Clearly, the points mentioned above raise issues about citizenship and solidarity, within both health and forensic genetic technologies, in a positive sense: how should we as citizens contribute to wider endeavours serving to improve both health and security? (And Barbara Prainsack has written extensively about these issues, of course)
- But both domains illustrate how such notions of solidarity and citizenship can be recruited and deployed in a contrasting rhetoric that reveals ideas about the role of the state and bio-power:
  - **E.g. as García-Deister & López-Beltrán (2015) argue,** ‘...*The comparison [between health and forensic genetic biotechnologies] also provides a vista onto discussions regarding the involvement of genetics in regimes of governance and citizenship and about the relationship between the state and biopower in a context of perceived health crisis and war-like violence.*’
- There is a need for further similar research studies:
  - They remind us to be constantly alert to the questions of what is the ‘proper scope of government access to a person’s genetic material’ (Murphy, 2016:367)
- There is a need also to be alert to developments in the near and mid-term future and the possibility that any remaining walls between the two domains will ‘evaporate’ as the science in both these domains is rapidly changing. (Murphy, 2016)

**Studies of, and suggestions for, effective governance structures are much needed; but need to show awareness of, and take into account, the other four lines of inquiry suggested above.**

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