

Summary of talks at ESRC Research Seminar 4: Comparing forensic & medical genetic technologies

ESRC Research ‘Seminar series on genetics, technology, security and justice. Crossing, contesting and comparing boundaries.’

Wed, 23 November, 12:00-17:30, Northumbria University, The Great Hall, Sutherland Building, Northumberland Road, Newcastle upon Tyne, NE1 8ST.

Niels Morling (University of Copenhagen) - Forensic Genetics: Ethical Considerations

Morling provided an overview of the forensic practices in Denmark and then discussed 4 situations that present ethical dilemmas. Underlining the importance of a multidisciplinary approach incorporating police forensics, forensic genetics and basic science, Morling took each situation in turn, discussing accidental findings, familial searching, searching of other databases (such as medical databases for information to aid a police investigation) and extrapolating physical traits from genetic ancestry. With each example, he explained the process in Denmark and highlighted some of the questions they raise, such as: What can and should be done? Should these techniques be used? How do we safeguard their use? Morling ended his talk by drawing attention to some of the limits of DNA and its claimed uniqueness, problematising the lack of discussion on such issues within the forensic genetics community.

Bronwyn Parry (King’s College London) - Legitimizing “Spaces of Exception” in data exchange: Family reunification; trafficking and the ‘war on terror’

Parry argued that the interoperability of forensic and medical databases can be of benefit in a number of ways but also raise serious questions about consent and the autonomy of the donor. Such interoperability has clear implications for public confidence, particularly in terms of medical confidentiality. Parry’s talk explored a number of cases where medical data and databases have been used in forensic work. Drawing on Agamben’s concept of “spaces of exception” to conceptualise situations where state powers are expanded (such as to use medical data to aid police investigations) and justified based on a perceived or real threat, Parry explored the use of genetic information in the investigation of Anna Lindh’s assassination; identifying the “living disappeared” in Argentina; human trafficking; and in the apprehension of the ‘Bind Torture Kill’ (BKT) serial killer, Dennis Rader. Each of these examples highlighted situations where exceptionalism was used as a means of justifying the use of extraordinary measures. The final example of the identification and apprehension of Dennis Rader, occurred as a result of obtaining a historic pap smear test taken from his daughter (without her

consent) and comparing the resulting DNA profile with profiles obtained at the crime scenes. Parry's talk raised numerous questions about this exceptionalism, the limits and the implications, particularly in the negotiation between an individual's autonomy and rights versus societal need or "public good."

Gethin Rees (Newcastle University) - 'The Second Victimisation': Forensic Medical Practitioners' attitudes to standardisation in forensic evidence collection

Rees provided a different perspective on the interface between forensic and medicine, drawing on forensic medical professionals (doctors and nurses) as they collected evidence in sexual assault cases. Exploring the notion of standardisation in relation to the collection of trace materials from the bodies of victims, Rees gave an overview of some of the standards in place limiting contamination. In particular, he highlighted some of the tension inherent in enacting guidance, particularly when there are limits to the information that is available at the time samples are taken.

Juxtaposing Forensic Medical Practitioners' attitudes and practices of collecting trace material (and avoiding contamination of potential evidence) from victims of sexual assaults in the UK and Canada, Rees suggests two general approaches: "total collection strategy" and "quiet questions." The former focused on collecting evidence and avoiding contamination by collecting all potential trace material and bodily samples at the earliest possible moment, irrespective of the state of the victim, reflecting some of the standardised guidelines. The latter used questioning to nurture a more therapeutic relationship (more in line with ideas of the patient/nurse encounter), gaining information about the case and using this to make decisions about what should and should not be collected. In doing so, Rees brings into stark relief how standardised and rigid guidelines and the way they are operationalised may not offer space to consider the autonomy of the victim or the therapeutic aspect of medical work.

Barbara Prainsack (King's College London) – The datafication of everything? Effects on the convergence of forensic and medical bioinformation

Prainsack situated the discussion on data in recent vision of the future of healthcare. Health Secretary Jeremy Hunt's vision that the human ability to make diagnostic decisions are superseded by (and in places pitted against) computers is exemplary for how policy makers and others envisage the future of healthcare. The consequences of such visions are tangible: Rather than investments in young doctors, large investments are made into the creation of digital infrastructures and resources that are

in turn hoped to integrate and utilise various types of data to personalise healthcare. Practices such as these and the ideology they represent, where the machine and machine-generated data are placed at a higher point in the hierarchy than human work or judgement, fall under what has been termed datafication. The phenomenon of datafication, the process of translating the world into data, including those things that you may not believe relevant or necessary at the start, is used by Prainsack to explore the enactment of certain understandings of the power of data, including the recent UK Investigatory Powers Act expanding the potential for security services to access an individual's personal communications without them knowing. Prainsack concluded by arguing that the increasing gap in power and control between those who use data (typically corporations), and those who give data (citizens) cannot be closed merely by increasing individual control over data use; we also need to strengthen collective responsibility, oversight, and ownership of the infrastructures and tools for data use in the domain of bioinformation and beyond.

Simon Woods (Newcastle University) – Framing common goods: From genomics to forensic ‘big data’

Woods explored the interface of medicine and forensic science using examples from two big science projects, RD-Connect and Genomics England. Raising a number of questions about the potential for different uses of such large datasets, and issues around how we protect privacy, Woods puts forward four “primary goods” that, in part, help to make sense “common good”. These goods, “liberty”, “wealth”, “health”, and “justice”. Each of these goods have certain means and values attached. In “health” for example, there are values of respect for the person's autonomy and privacy. There is an expectation of confidentiality and statutes in place which, to some extent, safeguard this. Focusing on health and justice, Woods took each in turn to demonstrate the tension between public interests and private rights in discussions of linking or using data across ‘primary goods’ – i.e. using data initially collected for one purpose and using it for another. Although laws may limit the potential for the use of such data in other contexts, there is potential for a function creep from bio-data and biomaterial, to big data and, at an extreme, open data with levels of control decreasing the closer you get to open data. Reflecting on the potential, Woods concluded by raising a number of questions about the type of world we want to live in and how we might protect this vision through governance practices.