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ADELPHI GENETICS FORUM

exploring heredity and society

Adelphi Review

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Adelphi Genetics Forum, 19 Northfields Prospect, London, SW18 1PE

Tel: 020 8874 7257 www.adelphigenetics.org

General Secretary: Mrs Betty Nixon

executiveoffice@adelphigenetics.org

Review Editor: Mr Robert Johnston

Charity No: 209258

EDITORIAL

In this issue we explore some of the key aims of the Adelphi Genetics Forum. Firstly, we have 'My Life in Genetics' with one of our Vice-Presidents, **Professor Greg Radick**. Greg is a renowned researcher of the history of genetics and in his article, we discover the sources of his interests and skills. We must also congratulate him on winning the Genetics Society's prestigious JBS Haldane Lecture Award for 2025.

Secondly, we have the latest report from CHASE Africa, recipients of grants from the Artemis Trust of the Adelphi Genetics Forum. They have used these to great effect in Kenya where they improve access to healthcare and remove barriers to family planning for remote rural communities. They work so hard in difficult circumstances.

Finally, we have reports from two conferences we have supported, both of which aim to improve the study and understanding of human populations. The British Society for Population Studies take a broad but comprehensive view whereas the Thalassemia and Sickle Cell Disorders Conference looks at the specifics of a number of families in Wales.

I should also like to draw your attention to pages 30-31 where you'll find details of this October's Annual Conference on **'Population Genomic Screening – Exploring its Complexities'**, planning for which is well underway.

Robert Johnston

My Life in Genetics

An Interview with Professor Greg Radick, Vice President of the Adelphi Genetics Forum

Greg Radick

You originally studied history at Rutgers University, in your home state of New Jersey. What first drew you to studying the history of science in general and genetics in particular?

When I started at Rutgers in 1988, I was equally drawn to science and the humanities. I decided for the humanities mainly because of the terrible teaching on the Calculus 101 course I took, though I hoped that by majoring in history I could nevertheless keep my options as wide open as possible. At that time, I wasn't aware of something called "history of science," and some-

how or other I ended up not taking any courses taught by members of staff whom I later discovered to be well-known historians of science and technology. But in an idiosyncratic way I kept bumping up against the subject: in a reading course in sociology classics where I was assigned Thomas Kuhn's *The Structure of Scientific Revolutions* (1962); in a quantum-physics-for-poets enrichment seminar that used an amazing survey textbook, *Introduction to Concepts and Theories in Physical Science* by Gerald Holton and Stephen Brush (1973); and in a course on the history of the indigenous peoples of the Americas taught by a remarkable teacher with a remarkable name, Calvin Luther Martin, who, in a way that captivated me, made vivid the differences between Western and indigenous "thoughtworlds," with their radically different conceptions of history, knowledge, nature, humankind's place in the grand scheme, and so on.

This fitfully fed appetite for science got stronger thanks to the reading and pondering I did in the two years after I graduated from Rutgers in 1992, during time off from a very enjoyable job as an English teacher at a secondary school in Prague. I was especially enthralled by the work of Stephen Jay Gould, George Steiner (a literary critic who chastised humanists for their ignorance of science and mathematics) and Oliver Sacks, whom I read mainly in marvellous pieces he published in *The New York Review of Books*, which was on sale in my favourite bookshop in Prague.

Reckoning that the way to bring science into my life in a full-time way was to go to medical school, I went back to Rutgers for a year to study all of the science and mathematics that I needed in order to pass the US medical school entrance exam. I started with Calculus 102 (which was well taught, and which I loved), followed by the first-year courses in physics, biology, chemistry and organic chemistry. Intellectually I was over the moon, and was convinced

I was now on the right path. But by then I had an English girlfriend (now my wife) who had a contract to be a trainee solicitor at a law firm in Cambridge, so I got hold of Cambridge University's catalogue of master's degrees to see if I could maybe find something to occupy me for a year before I made the medical-school plunge. That was where I first saw the words "history and philosophy of science." I'd had no idea that there was a name for the sort of thinking about science which, if I was honest with myself, I preferred to the doing of science, let alone that you could study it as a degree. That turned out to be a life-changing moment of discovery. Happily, I got admitted to the Cambridge MPhil in History and Philosophy of Science in 1995; and though I went on to take (and do pretty well on) the medical school exam as career insurance, I was able to stay on at Cambridge for the PhD, eventually writing a thesis that became the basis for my first book, *The Simian Tongue: The Long Debate about Animal Language* (2007).

As for the history of genetics, my first engagements with it were as a teacher: initially as a tutor on the Cambridge second-year survey course in the history of science; and then, more extensively, as a substitute lecturer for a third-year course on "Darwinism, Genetics, and Social Science," taught by the sociologist Martin Richards. It was while searching for images to illustrate my lecture on the 1900 rediscovery of Mendel and its aftermath that I first encountered a photograph that became very important for me. Published in February 1902 at the end of a searing critique of Mendel's paper by the Oxford biologist and Mendelism critic W. F. R. Weldon, it shows – contrary to Mendel – garden peas whose colours form a green-to-yellow spectrum. Right away I sensed that there was something here worth pursuing further. In 2000, as I was finishing up my PhD, I brought a copy of Weldon's photograph with me to a job talk at Leeds

for a lecturing position in its wonderful Division of History and Philosophy of Science, by way of indicating the direction of my future research. I had the immense good fortune not only to get the job but to inherit the historian of biology Robert Olby's old course on the history of genetics, enabling me to continue learning by teaching.

By 2012, when I gave an inaugural lecture after my promotion to a professorship at Leeds, I had figured out in a general way what I wanted to say about Weldon and the controversy over Mendelism, and I used the lecture to set out the themes of the book I hoped to write. Especially fascinating to me was the contrast in the visions for the science of inheritance between the Mendelians, who emphasized the centrality of either/or character binaries caused by nothing but allele combinations "for" those characters (think of Punnett squares), and Weldon, who instead emphasized characters that are conspicuously variable depending on differences in internal and external environments. Completing the research and the writing took me another ten years, but I got there in the end: *Disputed Inheritance: The Battle over Mendel and the Future of Biology* – with Weldon's pea-spectrum photograph on the cover – came out in 2023.

What are your main areas of study at present?

Genetics and its history continue to loom large. One ambition I've had for a long while is to publish a scholarly edition of the "Theory of Inheritance" manuscript that Weldon was working on when he died unexpectedly in 1906. Now that *Disputed Inheritance* has piqued curiosity in that manuscript, and in Weldon more generally, I think it's high time to bring that project to fruition, which I hope to do with several history-of-science and scientific collaborators. A

different but no less Weldonian collaborative project also coming to fruition is an experimental study of genetics pedagogy led by the educational psychologist Brian Donovan, the biologist-educator Michelle Smith and me. Thanks to National Science Foundation funding, we've been able to push to the next level of rigour work begun at Leeds over ten years ago looking at the impact on university students of translating those Weldonian emphases on variability and environments to the introductory genetics classroom, in particular on students' ability to learn about genetics without picking up the misleading and pernicious notion that DNA is destiny.

In my own right, I've got a number of talks lined up that will give me a chance to develop further my claim in *Disputed Inheritance* – not original to me, but I've got my own take on it – that molecular knowledge about inheritance owes little to distinctively Mendelian knowledge, in that the former would have emerged with or without a prior Mendelian heyday. Especially on my mind right now, however, is my text for the 2025 JBS Haldane Lecture, which I'm deeply honoured to have been awarded by the Genetics Society, and which I'll be delivering in Cambridge in June.

Beyond the history of genetics, I'm very pleased to be working with Leeds colleagues and students, current and former, on a volume meant for the general reader and giving permanent form to a public lecture series we put on back in 2016 and 2017 called "History and Philosophy of Science in 20 Objects," featuring objects from our Museum of the History of Science, Technology and Medicine, including an X-ray camera used in the 1930s at Leeds to take the first X-ray crystallographic photos of DNA. (The research was done in the textile physicist William Astbury's lab by Florence Bell, the Leeds counterpart to Rosalind Franklin.) And I have quite a few other writing projects in various stages on the go, including a chapter I'm finishing up for a handbook on "integrated history and

philosophy of science" about counterfactual history of science.

From the beginnings of my studies in history of science I've been intrigued by the ways in which the authority of scientific knowledge is bound up with the notion of its inevitability – with, that is, its reputation for transcending the accidents of personality and, more generally, the accidents of human history, so that, no matter the historical particulars around a discovery or invention, in a deep way they don't really seem to matter, in that the discovery or invention would have come about anyway given other histories, with different personnel, circumstances and so on. No less intriguing to me has been the related puzzle of how we make plausibility judgements one way or other about claims as to what might have been in the scientific past.

To return to the Leeds experiment in teaching Weldonian genetics: I got the idea for it as a way of assessing the counterfactual potential of that manuscript that Weldon never lived to complete and publish. What if this ordinarily robust forty-six-year-old had survived pneumonia in spring of 1906 and then gone on to finish and publish that manuscript, in which, more fully than he had managed anywhere else, he set out the theoretical and empirical case for treating context dependency in hereditary characters as the rule rather than, as per Mendelism, the exception? It occurred to me that an indirect way of answering the question was to try to teach introductory genetics as if the curriculum had emerged from the Weldonian past that never was but might have been – a curriculum which, in line with Weldon's views, anchored students on examples in where the modifying role of environments was unmissable.

To my permanent amazement, I got a grant which then enabled a small team of us to give it a go. What we found was that, whereas students at the end of the standard start-with-Mendel

course on average were as deterministic in their attitudes towards genes as they were before teaching – in other words, that nothing learned in between had disabused them of the notion that DNA is destiny – students who'd taken the Weldonian course were on average less deterministic about genes. At least among the genetics educators I spend time with, that's a win: the more you know about genetics, the less confident you should be that you can read off phenotype from genotype.

It has been a thrill to see how the Leeds experiment has fired the creative imaginations of biologists and biology educators when it comes to exploring new options for teaching genetics in the present. But a major element of the thrill for me is the link with the initial ambition to improve the evidence base for judging an old but unrealized option in the scientific past. In that spirit, my handbook chapter is very much conceived as a how-to guide, by way of encouraging readers to "go there" in raising their own counterfactual questions about the history of science and in bringing evidence to bear in trying to answer them.

You're a member of the Board of Trustees of the Science Museum Group. What does this involve?

The role has two aspects. One is inward-facing, and mainly involves working with the other trustees to serve as a "critical friend" to the Director and other members of the executive team in the running of this enormous and extraordinary institution, comprising five museums – the Science Museum in London, the National Science and Industry Museum in Manchester, the National Science and Media Museum in Bradford, the National Railway Museum in York, and Locomotion in Shildon – plus the newly opened Science and Innovation Park near Swindon. The other aspect is outward-facing and amounts to acting as a sort of am-

bassador in helping the Group achieve its goals, in fund-raising but also in other areas.

As the sole historian of science at board level, I'm especially keen to fly the flag for the Group's extensive collections of historic objects, books and archival documents, as assets in presenting science in the public galleries and exhibitions but also as potential foci for research by my fellow historians. I was involved for a while in the Royal Society's Lisa Jardine grant scheme, which has been a great success in recent years in animating research on the Royal Society's collections by funding extended visits from early-career historians from Britain and beyond; and I would love to see something comparable for the Science Museum Group. So, if anyone reading this is minded to be philanthropically generous along these lines, do get in touch!

On what roles do you think the Adelphi Genetics Forum should concentrate?

In line with the recent name change, the Forum has identified a very important as well as distinctive niche for itself in supporting public discussion and scholarly research on the past, present and future of genetics, so I'm very much cheering on the organisation and its current priorities, including of course the publication and dissemination of this *Review*.

I'm also really pleased to lead the recently founded Working Group on the History of Eugenics, where I've been working with Shirley Hodgson and Marius Turda to help continue what we see as the organization's honourable tradition, begun back in Galton Institute days, of extending that support to discussion and scholarship on the history of eugenics. At our suggestion, the Forum recently made freely available the scans of three outstanding Gal-

ton Institute volumes from the late 1990s and early 2000s on the intertwined histories of genetics, eugenics and social Darwinism, and the positive response I've received from the history-of-science community indicates that our efforts along these lines are really appreciated.

Tell us something about yourself that isn't widely known

Although my undergraduate major at Rutgers was in history, my minor was in music, and I now play bass – my main instrument (though I can get around a little on piano and guitar) – in a jazz collective with fellow amateurs in Ilkley, the town where I live in the north of England. I'm not anything like as good a musician as I should be after forty-plus years of playing and even some formal study. But practice helps, and hope springs eternal…

Gregory Radick

Previous contributors to the *My Life in Genetics* series:

Published in the ***Adelphi Review:***

Professor Shirley Hodgson	Issue 6
Dr George Burghel	Issue 5
Dr Helen Middleton-Price	Issue 4
Professor Nick Mascie-Taylor	Issue 3
Mr Robert Johnston	Issue 2
Dr Jess Buxton	Issue 1

Published in the ***Galton Review*:**

Professor Nicholas Wood	Issue 15
Professor Dallas Swallow	Issue 14
Professor David Galton	Issue 13
Professor Andrew Read	Issue 12
Professor Veronica van Heyningen	Issue 11
Professor Dian Donnai	Issue 10
Professor Philippa Talmud	Issue 9

Improving access to Sexual and Reproductive Health and Rights (SRHR) information and services in the Tana River ecosystem, Kenya

A progress report for the Artemis Trust July-December 2024

Implemented by CHASE Africa's partner organisation, Communities Health Africa Trust (CHAT), this project addresses the unmet need for sexual and reproductive health (SRH) services for marginalised rural communities in the semi-arid region of the Tana River ecosystem, Kenya. The project provides access to sexual and reproductive health and rights (SRHR) information and services through door-to-door visits by Community Own Resource Persons (CORPs) and a back-pack nurse, referrals to health facilities, and mobile clinics. In addition, the project also assists communities to strengthen self-sustaining governance structures, which will advocate for the communities' health services, leading to long-term sustainability of the project outcomes. During the reporting period of 6 months, it was projected that we would facilitate 3,083 attendances for information and awareness-raising, and facilitate 867 family planning services.

The Guttmacher Institute calculated that between 2015-2019 there were a total of 2,380,000 pregnancies in Kenya annually. Of these, 1,450,000 pregnancies (61%) were unintended. This project is part of our long-term programme to improve knowledge of SRHR, fostering informed decision-making and health-seeking behaviours within communities in the Tana River ecosystem.

RECENT ACTIVITIES AND PROGRESS

Three Community Own Resource Persons (CORPs) (plus a fourth CORP in December) engaged in community dialogues and door-to-door visits, to raise awareness and discuss matters of Sexual and Reproductive Health and Rights (SRHR) with community members. CHAT works in collaboration with the Ministry of Health, frequently running joint outreaches staffed by both CHAT and MoH staff. Community Health Patrons (CHPs) linked to local government health facilities, often accompany CORPs as they engage with the community to enhance knowledge and understanding of SRHR. This provides the CHPs with training and practical experience, equipping them to continue such activities after our project intervention in those communities comes to an end.

Household visits and dialogues gave CORPS the opportunity to identify healthcare needs and refer individuals to local health facilities, as appropriate. However, often in the remote outreach communities there are no accessible health facilities, so where local services were not available, and services were not accessible, the CORPs arranged for our project ‘Back-pack Nurses’ carrying medical supplies to visit the communities to deliver vital SRH and other health services.

In addition, CHAT deployed two mobile clinics to ensure that those living in the most remote areas could be reached. These mobile clinics transport medical provisions and provide health care services across marginalised communities over a 10-day period, relocating to different nearby villages every 1-2 days, depending on the population density and demand.

CHAT works to strengthen Community Health Committees

Backpack nurse crossing the river from Tharaka to Mwingi

(CHCs). CHCs are made up of local community members, established to actively participate in the delivery of local health services, ensuring community needs are addressed and hold healthcare providers accountable at the grassroots level. Their function is essentially to act as a bridge between the community and health facilities within their area. 3 Community Health Committees were strengthened during this reporting period – 2 in Mwingi North and 1 in Tharaka Nithi South. 15 participants each. The Community Health Committees were supported by the CORPs to engage in community-led advocacy to address challenges in the local healthcare system, such as lack of commodities at the health facility

and lack of trained Health Care Workers at the health facilities. CHAT's nurse acts as an important mentor for newly trained MoH healthcare workers, improving skills in both inserting and remov-

Mobile clinic - the clinic visits each community one day each month

ing long-acting reversible contraception (LARCs). MoH facility level Community Health Promoters were trained to provide contraceptives, 7 in Tharaka Nithi and 5 in Mwingi North sub-county.

CHALLENGES ENCOUNTERED

Activities along the Mwingi North border with Garissa County face occasional security risks from Somali herders (Shiftas) who encroach communities to graze their animals during dry seasons, and conflicts can arise. There is evidence of the herders sometimes being armed and aggressive, and it is important to review

regular security updates from local leaders and CHPs to assess the situation before conducting outreaches. This consideration sometimes necessitates changes to outreach timings and locations.

IMPACT NUMBERS

Attendances for SRHR information and awareness-raising were: 19 years and under 1079, 20 years and over 2334. This surpasses the total projected reach of 3,083 for the reporting period, due in part to an additional CORP being supported in December. Family planning prescriptions provided were: 19 years and under 390, 20 years and over 1,577.

This surpassed the total projected provision of 867 family planning prescriptions for the reporting period. The effectiveness of the information and awareness-raising is evidenced by the fact that family planning prescriptions were provided to 1,059 first-time users of modern contraceptives. 1,116 other non-family planning sexual and reproductive health services were provided. These services included: HPV vaccines (15-18 yrs girls), cervical cancer screening referrals, ante-natal care referrals, HIV testing and counselling referrals. In addition to these, 534 non-SRH primary health services were provided, including immunisations, deworming, and treating a range of common minor ailments.

CASE STORIES

During door-to-door visits in Mutairu Village, Mwingi North, Lucy, a CHAT CORP met Syunthi, a single, visually impaired widow with three teenage daughters. Syunthi was left to take care of her family after her husband's death, and her daughters, aged 18, 15, and 13, all became teenage mothers, forcing them to drop out of school. CORP Lucy introduced to them the concept of family

planning so that they could all make informed decisions regarding future pregnancies. With Syunthi's blessing, her daughters chose to adopt three-year contraceptive methods. Within a week, Lucy coordinated with a nurse from Ngomeni Health Facility to provide the services discreetly at their home. Inspired by this new sense of hope, the girls shared their experiences with other young women in similar situations, ensuring they, too, could access these life changing resources.

Ladies waiting for their babies to be immunised

Karimi is a 48-year-old teacher in Gataine village of Tharaka Nithi County. After 23 years of marriage without a child, Karimi was delighted, shocked, and scared when she discovered she was pregnant with triplets. Supported through the pregnancy and birth by CORP Mercy, Karimi survived a life-threatening delivery and welcomed two sons and a daughter. Motherhood, however, brought

new challenges. “Caring for three infants at my age was no small task,” Karimi says with a laugh. “Even taking them to the clinic felt impossible,” but CORP Mercy was able to arrange visits from a nurse at Tunyai Dispensary. Karimi confided in CORP Mercy her fear of another risky pregnancy. Mercy was able to tell Karimi about contraceptives to enable her to prevent another pregnancy. Karimi visited the health facility and chose a five-year contraceptive implant, giving her peace of mind and the freedom to focus on raising her triplets. “I feel like a weight has been lifted,” Karimi says. “I can now confidently raise my children without the worry of another pregnancy. I hadn’t realised family planning could bring such relief”.

We thank the Trustees of the **Artemis Trust** for supporting this vital project to improve access to Sexual and Reproductive Health and Rights (SRHR) information and services in the Tana River ecosystem, Kenya.

Claire Nicholls
CHASE Africa

Grants for conferences and workshops

The Adelphi Genetics Forum makes awards of up to £1000 to help meet the cost of organising and running conferences or workshops on topics relevant to the Forum’s aims. We will under special, exceptional circumstances increase funding up to a maximum of £2,000, if the request is well justified.

Full details of the grants can be found on our website at:
http://www.adelphigenetics.org/grants/grants-for-conferences-or-workshops/

The next deadline for grant submissions is 1st September, 2025

British Society for Population Studies Annual Conference

9-11 September 2024 at the University of Bath

This was our 51st Annual Conference and over 260 people participated, with 170 presentations in 50 sessions.

Strands came together on the familiar topics of Health and Mortality; Ageing; Families and Households; Historical Demography and Migration; Fertility and SRH, and Data Science. Alongside these, ONS curated three sessions on Developments in Official Statistics and Telling the Story in Statistics. New strands came forward on Violence and Abuse; on Demography of Disaster and Crisis Contexts and on Disability in Low- and Middle-Income Countries. The popular Critical Demography session again ran this year, and the Climate Change strand which has been a feature of the past couple of conferences, gained momentum with additional submissions and sessions.

The New Investigator scheme is aimed at highlighting the achievements of early career researchers in population studies, who have the potential to make a significant contribution to population studies in years to come. This year's winner was **Dr Alina Pelikh** (UCL) who spoke on *Changing life course trajectories of young people in England and Wales during the transition to adulthood.*

Additionally, members came forward with a variety of interactive event formats. There were workshops on *Network analysis* and on *The use of administrative data for population and migration estimates*. There was a postgraduate and early career breakfast event, where PhD and early career attendees had the opportunity to pick up tips on getting published from editors representing *Population Studies* and *Demographic Research* Abstracts from all oral & poster presentations can be found on the BSPS website at:

https://www.lse.ac.uk/international-development/research/british-society-for-population-studies/annual-conference

Plenary reports:

Plenary 1: - *Deconstructing natural fertility* - Heidi Colleran (Max Planck Institute for Evolutionary Anthropology)

Heidi began by introducing the Birth Rites team, an independent research group housed in the Max Planck Institute for Evolutionary Anthropology. The group, led by her, has, as one of its main objectives, the improvement of our understanding of the mutually reinforcing relationship between culture and demography.

This presentation focused on the influence of culture on reproductive decisions and how that created a specific demographic pattern that affected a group's demographic characteristics, which in turn impacted reproductive decisions. Heidi presents this as a self-reinforcing, cyclical relationship.

Natural fertility is not a useful concept. She argues that natural fertility does not have a positive definition. It is only defined in opposition to birth control ("modern" birth control, that is). She further sustained this point by arguing that there are many routes to low fertility, some of which do not require modern contraceptive methods. She also stated that "natural" fertility does not necessarily mean high fertility by presenting a series of examples from different ethnic groups with diverging rates of cumulative fertility. She concludes by stating that "natural" fertility is, in reality, a combination of biological and cultural influences on reproduction, even if they are not aimed at parity-specific stopping.

Ethnography is an essential method for rejecting natural fertility. She shows this by providing an in-depth analysis of Vanuatu's demographic landscape as well as reproductive norms and practices. She emphasised the use of control, shame, and guilt to pressure infertile women of reproductive age into reproduction as an example of a technology of reproduction.

Building a natural fertility population from first principles. Heidi presented the work done with *PopCulture*, an open-source software that creates models that use both culture and demography. Additionally, she showed the efforts they have gone through to validate their models against observed data and the difficulties they are having at ensuring a solid, all-around high fitness, partially due to the quality of the existing data.

Using ethnography to build better models. Heidi used the case of indigenous age categories of women in The Gambia. Instead of using biological age, they used the local age structure (based on the number of reproduction events), which generated a better fit. This exemplifies how ethnography is a valuable mechanism to improve demographic models.

Plenary 2 - Ian Diamond and Alice Reid *in Conversation*

As part of BSPS 2024's packed programme, we were fortunate to witness an enlightening plenary session featuring **Sir Ian Diamond**, UK National Statistician, and **Professor Alice Reid** from the University of Cambridge, discussing the future of population statistics and highlights from Sir Ian's distinguished career. Sir Ian Diamond is the UK's National Statistician, providing overall leadership for the Office of National Statistics (ONS). Professor Alice Reid is an established Professor or Demography at the University of Cambridge.

The conversation began with a discussion on how Sir Ian Diamond got into Demography. Ian spoke of how, although many of his peers sought to be actuaries, he was particularly inspired by the idea of statistics being used for a positive impact for the public. Ian shared his excitement when taking a course in Statistical Demography at LSE, which opened opportunities to use statistics for public good. He emphasized that labels like "demographer" or "statistician" are less important to him than the process of solving meaningful problems with the right methods.

The discussion shifted to the impact of the COVID-19 pandemic on public understanding of statistics. Ian reflected on how at the beginning of the pandemic, there was a data deluge and an enormous demand for information. Despite all this information, there was a dearth of insight. As a result, statistical communication had to evolve quickly to meet the needs of the public, leading to an improvement in visual communication and the ability to speak about data in an interesting and compelling way. Ian expressed that if we continue this path, there is a great opportunity to build on the progress made during the pandemic for the public to continue to receive well-communicated data and information – but that it is on us as scientists and statisticians to lead the way.

The conversation continued to discuss Ian's previous roles both in research and university administration. Ian recalled how much he had enjoyed teaching and was particularly proud of the over 40 PhD students which he had supervised. Ian spoke of how much he learned from each of his PhD students over the years. On research, Ian spoke of how he can do a lot of exciting research in his current role – research that stretches his brain and thrills him. When asked about his role at the ESCR, Ian spoke of how much he learned about research funding in the 1990s and the critical importance of social science.

The conversation concluded by discussing the future of public statistics, and particularly the census. Ian spoke of developing better and more regular flows of data to deliver an annual census – but that this will require continuous development and new digital data innovations. Ian spoke with excitement about a situation where citizens can access their information easily, and where we will be able to leave information about ourselves for future generations to learn from. Despite a discussion about how important the census can be for triangulation, Ian seemed optimistic for the future of official statistics.

The talk was rounded off with a Q&A with the audience, discussing

issues such as the benefits and challenges of linking data, focusing on the public good, and the importance of why we study Demography. This conversation not only provided a fascinating insight into the career of one of the field's leading figures but also underscored the evolving role of statistics in shaping public policy and education, especially in a post-pandemic world.

Early Career Plenary: *Changing life course trajectories of young people in England and Wales during the transition to adulthood*

Dr. Alina Pelikh (UCL)

As the recipient of the 2024 Anne Shepherd New Investigator Award, Dr. Alina Pelikh delivered an insightful Early Career Plenary titled "Changing life course trajectories of young people in England and Wales during the transition to adulthood" based on her doctoral dissertation. In the context of increased economic hardship and the liberalization of social norms, Dr. Pelikh's dissertation leveraged the British Household Panel Study and Understanding Society to study three major waypoints in the transition to adulthood in England and Wales: departure of the parental home, school-to-work transitions, and partnership and family formation. She delivered key findings about each of her three studies, focusing her plenary on differences by cohort. Her results were especially striking because the birth cohorts she analyzed were very close together in terms of timing, yet they were experiencing very different life course trajectories. Some of the findings included:

- The youngest birth cohort studied postponed leaving the parental home by ~1 year relative to the earlier cohorts

- Graduates born in the youngest cohort take 3x longer to find a job than those in the earliest cohort and non-graduates are 2x as likely to have a turbulent start to their employment

- Cohabitees in the earliest cohort had a 50/50 change of sep-

aration or marrying irrespective of gender, SES, etc., however, in the later cohorts, first cohabitation is likely to end in separation, again regardless of gender, SES, etc.

Beyond the findings of her dissertation, Dr. Pelikh used the plenary to discuss some of her own trajectory as a demographer: her master's degree in demography at the University of Rostock, her participation in the European Doctoral School of Demography, her journey as a PhD student at the University of Liverpool, and her transition into her postdoctoral fellowship at UCL. We often see research output without being able to appreciate the personal and professional experiences that researchers have, which shape those research outputs. Learning about Dr. Pelikh's trajectory as a researcher added richness to her research findings. From learning that she was initially inspired to study the transition to adulthood after attending a seminar by Professor Francesco Billari to seeing how she linked topics that were new to her (e.g., medically assisted reproduction) to topics that she had gained expertise in during her PhD (e.g., partnership stability), Dr. Pelikh's discussion of her own trajectory provided helpful insights to early career researchers on the *process* of how research is made. Dr. Pelikh also provided helpful perspectives on public engagement informed by her own experiences working with news outlets, policymakers, and civil society organizations, reminding the audience that as researchers we have a duty to explain to the public what we find in our academic work. Dr. Pelikh ended her plenary by discussing the work on mentoring and peer support in academia that she has been involved in. She concluded her plenary with a reminder that was useful to everyone in the audience, but one that I found especially helpful as an early career researcher: it takes a village.

Maria Gargiulo
London School of Hygiene and Tropical Medicine

Thalassemia and Sickle Cell Disorders in Wales – Is There a Better Future?

Butetown Community Centre

November 16th 2024

Thalassaemia and sickle cell disorders are two serious hereditary anaemias of global importance with at least 300,000 annual births. Wales is a low prevalence area for these disorders, with few opportunities for affected families and their carers to have informed discussion to build up their knowledge. They affect mainly, although not exclusively, people of Mediterranean, Middle Eastern, South Asian, Far Eastern, African, and African-Caribbean heritage, and require vigilance to overcome prejudicial barriers to fair and equitable service access.

In response to suggestions from the thalassaemia and sickle cell communities in South Wales, Friends of Cymru Sickle cell and Thalassaemia community interest company (FOCSCT CIC), strove to find a programme of talks about Gene Therapy and Gene Editing that were undergoing or had undergone clinical trials. The aim was to promote joint (service providers, potential recipients, their families and supporters) learning, discussion and understanding about these life-changing therapies.

With the financial help of **The Adelphi Genetics Forum**, **Wales**

Gene Park and **Friends of Cymru Sickle Cell and Thalassaemia**, the organisational skills of the latter two, and additional moral support from the **Sickle Cell Society**, the **Ethnic Minorities Youth Support Team (EYST)**, and **Diverse Cymru** we managed to unite people with these disorders, family members, advocates, local community-organisation supporters, internationally-renowned experts, local health professionals, and people responsible for both delivery of gene therapies and monitoring of their effects.

The context: A gene therapy manufactured by Bluebird Bio in which a normal beta globin gene is added to the beta thalassaemia or the sickle cell stem cells, known as betibeglogene autotemcel/

Members of the organising team

Zynteglo, ran into problems during clinical trials when two people with sickle cell disorder were diagnosed with blood cancer. Detailed studies showed that this was more likely to have resulted from an underlying condition which increased the likelihood to develop leukaemia in the person's own stem cells, exacerbated by stress on them to rapidly divide and repopulate the marrow, than from vector integration triggering the malignancy. Nevertheless, it was withdrawn from consideration by NICE in December 2022 and withdrawn from the European market by the manufacturer for commercial reasons although still available in the USA.

In November 2023, the MHRA (Medicines and Healthcare Products Regulatory Agency) authorised the use in the UK of a gene-editing therapy for beta thalassaemia and sickle cell disorders called exa-cel (exagamglogene autotemcel), also known as CASGEVY. In August 2024, NICE (National Institute for Health and Care Excellence) approved NHS provision of exacel treatment for transfusion-dependent beta thalassaemia but NOT for sickle cell disorders. Deliberations about its availability for sickle cell disorder are ongoing. This has occurred in the same year as withdrawal by NICE of two non-curative therapies for sickle cell disorder, Crizanlizumab and Voxelotor.

Before the meeting, twenty questions asked by attendees were circulated to the speakers. People wanted to know who can receive gene therapy, what does it mean for someone with beta thalassaemia or sickle cell disorder to receive gene therapy, will it be a cure, what are the risks, how will these therapies be delivered through Wales NHS?

All speakers gave excellent presentations and covered the is-

sues raised with diligence and honesty. Furthermore, their pooled knowledge helped answer an additional thirty plus questions raised on the day.

Speakers included:

Faith Walker, Paulette Palmer, Kyriakos Kanias, Professor Paul Telfer, Anthony Pemberton, John James OBE, Dr Kerry-Ann Holder, Dr John Lewis, Dr Hannah Crocker and Dr Jonathan Kell.

The presentations before lunch were chaired by **Mr Jemin Popat**, a 42yr old man with transfusion-dependent thalassaemia, and after lunch by **Dr Jonathan Kell**, consultant haematologist lead for the NHS Wales Specialist Hereditary Anaemias Service. Welcoming everyone with great warmth and charm, Jemin described the excitement and HOPE (word of the day!) felt by people affected by thalassaemia and sickle cell when hearing about potential new treatments and things that could make their lives better.

Feedback on the day was incredibly positive.

The long, transcribed version of the talks, containing additional links to information requested, and a video of the presentations is available on line: https://www.youtube.com/watch? Thank you everyone.

Alison May, PhD
(retired Senior Research Fellow, Cardiff University)

ADELPHI
GENETICS FORUM

Conference 2025
The Royal Society London
Thursday, 23 October, 2025

Population Genomic Screening - Exploring its Complexities

Genomic Screening is becoming widely used and in the UK the genomes of all 500k participants in UK Biobank have been sequenced. The UK also recently started two new initiatives; the 'Generation Study' to sequence the genomes of 100k babies, and 'Our Future Health' that aims to recruit and collect health data and blood samples on up to 5 million adults, with eventual 'feedback information about disease risks'.

Several questions arise concerning these studies: 1) at a practical level, e.g. the significance of a particular finding in non-symptomatic people with no family history; 2) on an ethical level, e.g. informed consent and long-term data storage; 3) a financial question, e.g. the true cost to health services beyond the screening process; and 4) the impact of a positive screening result on individuals and families.

This conference will explore examples of programmes that have worked, and those that have not worked. To help provide some understanding of the issues involved, talks will cover historical aspects of screening, new initiatives, ethical considerations, impact of findings on health services and families, implementation of new screening methods, and communication.

CONFERENCE 2025 (continued)

SPEAKERS:

Professor Richard Houlston
Overview of population screening programmes

Professor Diane B Paul
A historical perspective on the realities of newborn screening

Professor Felicity Boardman
Ethical considerations in screening programmes

Professor David Hunter
The clinical utility of common genetic variation

Professor Aroon Hingorani
Polygenic risk scores in population screening and disease prediction

Dr Philip Ball
Challenges of communicating the complexities of genomic data

Adelphi Lecture:

Dr Margaret McCartney
Challenges of population screening

Admission is **FREE**, but strictly by ticket, available from:
www.eventbrite.co.uk
or the General Secretary, Adelphi Genetics Forum,
19 Northfields Prospect, London SW18 1PE
executiveoffice@adelphigenetics.org
www.adelphigenetics.org
(optional sandwich lunch - must be booked with admission ticket)