

Genomics Network Evaluation

Executive Summary

Overview

In 2014 the ESRC Evaluation, Strategy and Analysis team began an evaluation of the ESRC Genomics Network (EGN), a major initiative funded by the ESRC to examine the social and economic implications of developments in the life sciences. The ESRC invested around £29 million in the Genomics Network between 2002 and 2013, which consisted of four Centres spanning five UK universities. These were:

- Centre for Economic and Social Aspects of Genomics (Cesagen), Cardiff University and Lancaster University
- Centre for Genomics in Society (Egenis), University of Exeter
- Centre for Social and Economic Research on Innovation in Genomics (Innogen), University of Edinburgh and the Open University
- Genomics Policy and Research Forum, University of Edinburgh

To summarise the evaluation criteria, the evaluation considered for the Centres and the Network as a whole: design and implementation, academic achievement and impact, engagement activity, economic and social impact, capacity building, collaboration, management, legacy and overall successes and weaknesses.

Centre for Economic and Social Aspects of Genomics (Cesagen)

Cesagen was a multidisciplinary collaboration between the Universities of Cardiff and Lancaster in which staff from social sciences and humanities worked with natural and medical sciences to address the social, economic and policy aspects of developments in Genomics. Cesagen's main objective was to investigate the economic and social factors that shape natural knowledge in Genomics and other life sciences. The Centre was directed by Professor Ruth Chadwick. In Cardiff Professor Paul Atkinson was Associate Director, and Professor Brian Wynne was Deputy Director in Lancaster. Professor Adam Hedgecoe was the Director during the final years. Cesagen received around £11 million core funding from the ESRC between 2002 and 2013.

Cesagen's agenda moved and evolved with some of the major developments in the life sciences that occurred during the funding period. Although volume of output and overall scientific accuracy were both found to be high, it was noted by peer reviewers who contributed to this evaluation that some of the outputs made relatively small contributions to the field. Researchers from a range of disciplinary backgrounds contributed successfully to the work of the Centre, but, as can be the case with such large and broad research Centres, there were suggestions that there remained some disciplinary silos.

An impressive quantity of diverse and, in places, original engagement activity was conducted, and important impacts were achieved in a number of areas. Cesagen's research contributed to more compassionate and dignified care of older people in hospital in the UK and to the adoption of the Nagoya Protocol (legislation which promotes the global conservation and sustainable use of biodiversity). The Centre also created opportunities for engagement between members of the public and Cesagen researchers, building knowledge and understanding of contemporary developments in science through the public engagement

programme 'sciSCREEN'. However, the effectiveness of some of the engagement methods and the extent to which impacts were achieved beyond the aforementioned examples is unclear. The Centre's activity to build capacity at postgraduate and postdoctoral level was broad and useful development opportunities were offered, but some were critical of the support provided by the Centre to those at these career stages.

Centre for Genomics in Society (Egenis)

Egenis was based at the University of Exeter and aimed to examine the development and use of the science and technologies of genomics. The Centre was multidisciplinary and encompassed a range of perspectives from social science, biology, and philosophy. The Centre was directed by Professor John Dupré, and received nearly £7 million core grant from the ESRC between 2002 and 2013.

The Centre produced a large quantity of academic output and covered a broad range of topics. The outputs nominated for review through this evaluation were generally very well regarded by peer reviewers and manifest genuine interdisciplinary working. The level of scientific accuracy across the Centre's outputs was particularly high in the areas of evolutionary biology and genetics.

Egenis engaged users through a wide range of activity and achieved a number of impacts. The Centre's research has led to greater understanding of the interaction between society and medicine in diagnosing ADHD and Autism spectrum disorder amongst people with autism, their families, interested members of the public and relevant professionals. Egenis research contributed to improved prenatal genetic testing throughout the UK which in turn has helped to ensure robust quality assessment across European laboratories and in healthcare settings. In addition, the Centre's research on stem cells contributed to the safety and effectiveness of cross-national regulations for stem cell research. However, evaluation participants did note that on occasion the subject matter that the Centre focused on may have limited the opportunities for policy engagement. Those at the Centre were highly positive about the opportunities provided to both PhD and postdoctoral researchers at Egenis, and the destinations of those who have left Egenis were noted many times as the most significant capacity building achievement of the Centre.

Centre for Social and Economic Research on Innovation in Genomics (Innogen)

Innogen was based at the University of Edinburgh and the Open University. The Centre considered the evolution of Genomics and life sciences and their far-reaching social and economic implications. The multidisciplinary Centre comprised expertise in sociology, innovation, economics, business studies and governance of innovation, and received over £5.5 million core grant from the ESRC between 2002 and 2014. The Centre was Directed by Professor Joyce Tait during its first phase, and Professor David Wield during its second phase.

Innogen's comprehensive, coherent and unified programme of policy-oriented research with an important international dimension and an emphasis on genuinely interdisciplinary working demonstrates the Centre's success in these areas. The Centre's engagement activity, some of which involved working particular closely with the Genomics Forum, seemed to attract an appropriate range of audiences. The Centre also built on existing research capacity and

enhanced the careers of its researchers, and a large number of early career researchers at Innogen have gone on to more senior positions.

The centre achieved a number of impacts. Innogen's work on stem cell regulation in Argentina made a key contribution to the development of knowledge about the norms and values driving the formation of new regulatory structures, and helped to overcome a regulatory impasse in stem cell research in that country. Innogen's contribution to the UK Nuffield Council on Bioethics's inquiry into the ethical issues raised by biofuels resulted in a timely report that set out an ethical framework to guide policymaking for biofuels and attracted the interest of senior policymakers in the UK and the EU. Innogen researchers developing guidance for targeted R&D policies to promote the biotech sector in Europe helped to overcome a major barrier to effective biotechnology policymaking in Lithuania by creating opportunities for constructive discussion between two key Ministries and recommending the creation of an independent steering committee.

Genomics Policy and Research Forum

The Genomics Forum, based at the University of Edinburgh, was designed to integrate the diverse strands of social science research within and beyond the Network; to develop links between social scientists and scientists working across the entire range of genomic science and technology; and to connect research in this area to policy makers, business, the media and civil society in the UK and abroad. The first Forum Director was Professor Michael Banner and Professor Steve Yearley became Director in 2006. The Forum received a total of £5 million from the ESRC between 2004 and 2013.

The Forum exploited a number of synergies across the work of the EGN Centres, and engaged many different audiences on various issues covered by the EGN. The Forum had good working relationships with the EGN Centres and led on a broad range of activities on behalf of the Network. The well-regarded Visiting Research Fellowship programme offered by the Forum saw over 100 fellows contribute in various ways to the work of Forum, and benefit from the training and development opportunities that it offered (as did the early career researchers based at the Forum).

A number of non-academic impact achievements were reported. The Forum influenced thinking around the limitations of technology concerning DNA analysis for attributing nationality to an individual, made contributions to broad debates around biotechnology and to synthetic biology development and policy via a Working Party of the OECD, and demonstrated the importance of networks, relationships and of collaborations between social and STEM scientists.

The Genomics Forum faced a number of challenges, which may have hampered its achievements. The Forum was established two years after the other Centres, meaning that its activities needed to be retrospectively integrated into the existing programmes of engagement activity planned by the other Centres. Although the work of the Forum and Centres became more complementary during the second funding phase, there was an initial lack of integration and alignment in some places.

The Network

The ESRC made a considerable investment in the EGN and a mass of activity was conducted by the Network. The number of outputs produced by the Centres was high, but levels of

citation and quality as assessed by the peer reviewers appointed as part of this study were more varied, and the international reach of the Network could have been greater. The degree of interdisciplinary working varied across the Centres. There is no doubt that each Centre housed academics from a variety of disciplinary backgrounds, but the extent to which the ways of working and the outputs produced could be described as interdisciplinary is mixed.

A large quantity and diverse range of engagement activity was reported across the Network. This included conferences, presentations, workshops, membership on advisory boards and a range of public and policymaker engagement activities. The activities which targeted the general public and that brought a range of individuals with different backgrounds together were highlighted as particularly valuable by those involved in the Centres. A broad range of impacts was achieved by the Centres. UK government thinking and policy, activity in the NHS, and international policy and regulations were all reported to have benefitted from the work of the Genomics Network. Contributions to issues concerning a number of complex ethical issues were also made.

There was effort on the parts of the Centre Directors and others to avoid duplication and ensure that the Centres and the Network offered a cohesive and well-balanced range of activity. Although the EGN Centres collaborated in a number of areas, including the EGN book series and journal special issues, on joint events and conferences, and through the EGN newsletter and web portal, some of the evaluation findings suggest that the EGN's research profile was not coherent, contained gaps and that there could have been more synergy. Indeed, staff across the EGN noted that the Centres generally operated separately, despite efforts from the Genomics Forum to help address this. This evaluation was unable to identify many examples of scientific or impact achievement that involved the whole Network. It is also unclear as to whether the Genomics Forum, introduced two years after the Centres, ever managed to bring together the work of the three research Centres at the level it was designed to do. The Network Advisory Group, comprising the Centre Directors and designed as another tool to bring cohesion to the network, could have played a greater part in this.

There is a legacy to the ESRC's investment in the Genomics Network. A large cohort of researchers have benefited from their involvement in the Network. The three research Centres have become sustainable without requiring further ESRC funding. However, the Network itself and the Genomics Forum have ceased to exist, preventing any substantial legacy of these elements of the Network's collaborative activity. The Centres responded well to the (often fast-paced) changes in the Genomics field, but debates have moved on significantly during the 11 years of EGN funding, and none of the evaluation participants noted that further social science funding is needed in this area. Instead suggestions for future activity for the ESRC mainly concerned focusing on the social dimensions of other life science topics and the use of Big Data to address such issues. Indeed, investing so much into one (particularly fast moving) area at relatively short notice, as the ESRC did with the Genomics Network, may not be the most appropriate way for the ESRC to ensure cohesive, purposeful research activity.