





# Foreword

## It is a great pleasure to present The Farr Institute Annual Report 2015/16.

Following his Eight Great Technologies Science speech in January 2013, David Willetts (the then Universities and Science Minister), announced funding for The Farr Institute in July 2013. The strategic aim was to strengthen the MRC coordinated, ten partner £17.4m award that had created four e-Health Informatics Research Centres (eHIRCs) in the UK in 2012. This assembled 21 UK Universities and two MRC Units to create four virtual research centres, hosted by the University of Manchester, University of Dundee, Swansea University and University College London (UCL). The eHIRCs had started to create much-needed multi-disciplinary informatics capacity (25 new senior academic posts) and were harnessing linked health data for discovery science, experimental medicine and data-intensive innovations in healthcare. A £400K per annum award created a Network across the Centres to support UK-wide communities of best practice, coordinated training, sharing of methodology and concerted engagement with the public, industry and the NHS.

The additional £20m MRC capital award provided e-infrastructure and physical buildings to lay the foundations of a more formal national distributed research facility across the Centres. The Farr Institute is named after William Farr (1807-83), who was a pioneer in early computation (with Babbage's Difference Engine) of health data, underpinning public health reforms.

Our vision for The Farr Institute is to unleash a bigger scale of public-serving research across the UK's health and health-related data assets, particularly those that can be linked for defined populations. UK data range from healthcare records to biological, social, economic and environmental observations. The bold aim of The Farr Institute is to establish the UK as the world leader in health data science research from scientific discovery to the enhancement of patient and public health.

There is an urgent need to move beyond the constraints of a classical 'research collaboration' that the original investments funded. The clear opportunity is to leverage the scale of the UK's diverse populations by creating an agile national ecosystem of universities, NHS, private companies and other stakeholder organisations. To achieve this will require a massively scalable apparatus that can enable large, multi-centre, deeply-phenotyped studies at local, regional and national levels, where the focus is the alignment of all available biomedical data per individual, with the ability to link health and healthcare history, genes, other biological information, environments, and lifestyles in a trustworthy way.

The apparatus and ecosystem that The Farr Institute is building is a vital first step for conducting 'big data' longitudinal studies: enabling a bigger return from larger investments such as UK Biobank and Genomics England; uncovering new 'phenomarkers' for precision medicine; and enabling rapid translation of science into more data-responsive healthcare, public health and economic developments.

The Farr Institute brand has rapidly become established internationally. There is no other national effort with similar aims, however, there is much to be done to realise this bold, ambitious and enterprising agenda. We are committed to working in partnership with colleagues across the UK to grasp this opportunity.

This report marks the achievements of the eHIRCs against their original objectives and contracts (of February 2012). We also describe how we have focussed the objectives of The Farr Institute; integrated existing activities; made a series of strategic recruitments; created outstanding inter-disciplinary research facilities in Swansea, London, Manchester, Liverpool, Dundee and Edinburgh; and developed the Institute's digital infrastructure.

Finally, we document how we are committed to working in partnership. The UK landscape will have to adapt if we are to be the come-to-place for health, biomedical informatics and discovery science research that exploits the nation's leadership position in life sciences, informatics and genomics.

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It is a very complex landscape and the cross-sectoral interdependencies are at times daunting. We report on joint working with many partners; a non-exhaustive list includes the Health and Social Care Information Centre (HSCIC); NHS England; NHS Scotland; NHS Wales; Northern Health Science Alliance (NHTSA); Research Councils UK (RCUK); Clinical Practice Research Datalink (CPRD); research charities including British Heart Foundations (BHF) and Cancer Research UK (CRUK); Innovate UK; Joint Information Systems Committee (Jisc); Association of British Pharmaceutical Industries (ABPI); Academy of Medical Sciences; Administrative Data Research Network (ADRN); Alan Turing Institute and the UK Health Data Analytics Network. The Institute is also working internationally with: The International Medical Informatics Association (IMIA); World Health Organisation (WHO); the Global Alliance for Genomic Health (GA4GH); National Institutes of Health (NIH); National Science Foundation (NSF); and with large-scale health data initiatives in the US, Canada, Netherlands, Sweden, Denmark, Australia, New Zealand, Canada, Singapore, China, Malaysia and South America.

Over the past three years, the Institute has started to put the UK on the global map of informatics and data science for health. We now seek to consolidate and extend this work and to work in partnership to realise the research value of the UK's considerable health data assets. This reflects the ambitious, far-reaching recommendations of our International Advisory Board, starting with the appointment of Dr Graham Spittle, our Strategic Advisor.

It has been a great privilege to have been invited to lead on the creation and establishment of The Farr Institute. This however has been an incredible team effort and we are enormously grateful to the outstanding scientific, clinical, academic and administrative teams across the UK who have worked tirelessly and with massive commitment to make the achievements described in this document possible.



**Professor Iain Buchan**

Iain Buchan is Clinical Professor in Public Health Informatics at the University of Manchester, where he founded and leads the Centre for Health Informatics.



**Professor Harry Hemingway**

Harry Hemingway is Professor of Clinical Epidemiology at University College London and Director of the Farr Institute in London.



**Professor Ronan Lyons**

Ronan Lyons is Professor of Public Health, Swansea University and Honorary Consultant in Public Health with Public Health Wales.



**Professor Andrew Morris**

Andrew Morris is Professor of Medicine, Director of the Usher Institute of Population Health Sciences and Informatics and Vice Principal of Data Science at the University of Edinburgh.

# Executive Summary

The vision of The Farr Institute is to unleash a larger scale of public-serving research across the UK's health and health-related data assets, particularly those that can be linked for defined populations. Our aim is to establish the UK as a world leader in health data science research from discovery science to the enhancement of patient and public health. The Institute was proposed by MRC in July 2013, in the belief that the UK has a unique global opportunity, built on:

- A rich tradition of UK excellence and innovation in using routine health (care) data for pioneering research stretching back over 150 years to when William Farr systematised the analysis of health data in England and Wales, with enduring impacts on public health and policy-making.
- Existing strengths in mathematics, biostatistics, epidemiology, genomics, bioinformatics, and computer science, but with limited health and biomedical informatics capacity needed for more integrative health data science.
- Academic excellence in a range of disciplines across the eHIRC Centres which could be readily complemented by forging collaborations with other centres of excellence across the UK and internationally.
- Internationally-recognised excellence in applied research with health data including our longstanding investments in UK birth and case cohorts, greatly enhanced by the existence of the NHS and allied public services where patients/citizens can be tracked across whole systems.
- The international commitment to precision medicine, that facilitates translation of basic scientific progress into clinical impact through effective research, underpinned by informatics, deep phenotyping and advanced analytics.

Delivery will require strong UK leadership, greater interoperability through widespread use of standards, new methods to support the integration of heterogeneous structured and unstructured data, and an inclusive approach to forge collaboration with

other initiatives and bodies [e.g. MRC Medical Bioinformatics Centres, Genomics England (GeL), National Institute for Health Research (NIHR), Health and Social Care Information Centre (HSCIC)]. It will also require the development of enduring partnerships among multiple academic, NHS and industry bodies and a rapid increase in the UK skill base. These are all critical factors in our quest to perform transformational science at scale and drive economic growth, whilst maintaining the trust of the public in everything we do.

At the first meeting of The Farr Institute International Advisory Board in December 2014, chaired by Professor Nancy Pedersen (Karolinska Sweden) five major recommendations were made to (i) Communicate a clear vision of the identity, role, remit, objectives and added value of The Farr Institute (the basis of this report);

(ii) Unify and integrate the research, education and expertise within each of the four Farr Centres (as reflected in the UK emphasis of this report); (iii) Deliver 2-3 cross-centre demonstrator projects which show the added value contributed by The Farr, (achieved – see research highlights); (iv) Take a national lead in placing public/patient involvement and advocacy at the heart of The Farr Institute; and, (v) Become a leader on best practice in Governance relating to health informatics research, working with similar organisations internationally to address governance issues that hinder global research.

**Box 1** sets out The Farr Institute objectives for 2015-16. In this 2015/16 Annual Report the progress and impact across these six domains is described.

## Box 1. 2015-16 Objectives

In 2015/16 The Farr Institute aligned its purpose and function and agreed six objectives designed to provide a powerful foundation for UK informatics and health data science;

1. Perform pioneering multi-disciplinary research with large and complex health-related data, including healthcare records, biological, social, and environmental data.
2. Enable new datasets and develop new infrastructure, methods, technologies, and standards for such research.
3. Develop skills, talent and expertise in individuals and research communities for collaborative working.
4. Work with the owners and controllers of data to support the safe use of patient information for medical research across the UK, championing data protection, confidentiality and privacy.
5. Engage with the public to demonstrate the benefits of using health data in research and to encourage the support of secure and trusted access to patient information.
6. Bring together government, public sector, academia and industry to foster relationships and establish best practices for innovation, discovery and impact in health data science.

## Delivery against objectives

**Research.** The Farr Institute has published 74 papers directly from the eHIRC funding (in a range of journals including Science, Lancet, BMJ, PLOS Med), across a breadth of research domains including public health, discovery science, precision medicine, learning health systems and ethical and social issues in relation to health records research (Appendix 1). A further 328 papers with other colleagues have been enabled by Farr-funded scientists and engineers.

The Farr Institute has established seven UK health data science research groups in Asthma (in collaboration with Asthma UK); Mental Health (with MQ); Renal Disease; Cancer; Drug Safety; Linking UK cohorts and Primary Care. Farr Investigators have leveraged an additional £68M in research funding since 2013 in areas including: cancer; dementia; industry engagement.

**Enabling new data sets.** Farr has worked with data controllers to start to provision new data sets for research including: national prescribing (100M per annum) and national imaging (23M since 2009) for the 5M population of Scotland; critical care data, laboratory data and the referrals dataset for the 3M population of in Wales; the National Neonatal Research Database and National Hip Fracture Database. The Farr Institute is committed to support NIHR and ELIXIR (the EU infrastructure for biological information) to create appropriate data discovery services for data assets to promote their availability on behalf of data controllers (whether NHS, Academic or other bodies).

**Capacity building.** The Farr Institute has created a UK wide doctoral training support programme for more than 70 PhD students and supported them with summer schools and symposia. Taught postgraduate masters courses, and online distance learning courses in health data science and technology have been developed in six member universities, matriculating over 400 students in 2015/16. 17 new faculty positions have been created across

Farr Institute partners in 2015/16. UK contributions to the top five journals and top three international conferences in health and biomedical informatics have increased substantially.

### Trusted Research Environments (TREs), policy and governance.

The Farr Institute subscribes to a model of interoperability delivered by a federated network of TREs that enables the identification and retrieval of all data that pertain to individual health. This requires a data sharing architecture that is capacious enough for all relevant data types and that enables patient and institutional autonomy to be respected. This is a grand challenge for the UK. In 2015, The Farr Institute received ISO27001 accreditation for five TREs across the UK in Swansea, London, Dundee, Edinburgh and Glasgow. Manchester is in the process of gaining accreditation. The Farr Institute has demonstrated thought leadership by influencing Government policy in Wales and Scotland to create single information governance sign off and scrutiny for cross-sectoral health data science projects. In addition, Farr-supported research led to Government policy to create a network of "Connected Health Cities" across the 17M population for North England enabling connections between NHS, local government (including social care) and patient-collected data in the quest to create the world's first true learning health systems in the UK.

### Thought leadership, public engagement and advocacy.

Senior Farr Investigators have been invited to deliver 45 plenary lectures during 2015/16 in the UK and 17 internationally. The Farr Institute has hosted high level day-long delegations from NHS England (Sir Malcolm Grant, Chairman), Innovate UK (Ruth McKernan, CEO), HSCIC (Andy Williams, CEO), Office for Life Sciences (George Freeman MP, Minister for Life Sciences) and the Scottish Council for Economic Advisors (Nicola Sturgeon, First Minister, and John Swinney, Deputy First Minister). Farr Investigators have contributed to the



Citizens' Jury, HeRC, Jan 2016



MS Life Conference 2015



Manchester Science Festival



Building new research collaborations:  
The Farr Institute International Conference,  
St. Andrews 2015

Caldicott Review, Academy of Medical Sciences reviews of Team Science and Public Health, the Nuffield Council on Bioethics review of 'The collection, linking and use of data in biomedical research and health care', and the multi-funder Expert Advisory Group on Data Access (EAGDA) hosted by the Wellcome Trust that has published several influential reports including the public perception of data use for commercial purposes (March 2016). The Farr Institute has championed the #datasaveslives campaign which has received 17,000 mentions on Twitter and has been promoted by organisations such as Cancer Research UK (CRUK), Public Health England (PHE) and the government backed Empower data4health campaign. The website attracted nearly 50,000 unique visitors over the past year and Twitter accounts have gained over 4,000 followers with a peak in activity of 43k impressions during The Farr Institute International Conference 2015. Investigators and projects from The Farr Institute have received eight mentions in the national press including three full length BBC radio interviews. The Farr Institute Directors were signatories on the letter sent to the Times on behalf of research institutes across Europe warning of the risk to research if the proposed change to the EU Data Protection Regulation had been adopted.

### Industrial/academic collaborations.

The Farr Institute, working with One Nucleus, the Catapults, Innovate UK and UK Trade and Investment (UKTI) has created a network of links to companies globally, across the pharmaceutical, digital health, biotechnology, informatics and data science industry verticals. Currently 15 active cross-centre projects are being developed (some are currently subject to non-disclosure agreements). Three have led to formal contracts.

The Farr Institute was the topic of a plenary address at several high profile national/international forums including UKTI, Drug Information Association (DIA) European Conference, Research Councils UK (RCUK) Research Innovate Grow event at Westminster and Expo Milan.

### Opportunities

Through its leadership roles Farr investigators are able to seize rapidly emerging opportunities in health data science. Farr investigators lead or collaborate with initiatives in Health North's Connected Health Cities, MRC Stratified Medicine, MRC Medical Bioinformatics Awards, Horizon 2020, Innovative Medicines Initiative (IMI) Big Data for Better Outcomes, Genomics England, Alan Turing Institute. As one example, the NIHR Biomedical Research Centres (current competition for new applications and renewals 2016) are likely to make substantial investments relevant to hospital

informatics. In Wales, five new Health and Care Research Wales centres and units have new investments in data science; cancer, population health, renal, primary and emergency care, and mental health. Across North England from 2016-2019 there will be pilots of four "Connected Health Cities" each with a civic-centred data analytic facility drawing on data from HSCIC and local sources, leveraging expertise from The Farr Institute in informatics and statistics. A Connected Health Cities Hub will work closely with HSCIC and Department of Health to inform plans for scaling data analytics across multiple health systems, enabling deeper discovery science, more coordinated discovery science and more agile translation of research into algorithms and actionable care information.

In Scotland, The Farr Institute will be a founding partner of the recently launched Precision Medicine Ecosystem, that brings together each Scottish medical school, NHS Scotland and the national Innovation Centres, sponsored by the First Minister of Scotland.

Looking forward, our bold plans for 2016-2018 are guided by our objectives, achievements to date, challenges and opportunities. For example, we will facilitate the development of new UK-wide research programmes. We will also propose to establish new UK-wide working groups in hospital informatics/



Delegates show their support for the #datasaveslives campaign at the Farr Institute International Conference 2015

analytics, genomics and electronic health record (EHR) integration for discovery science, precision medicine and intelligent trials. In developing Trusted Research Environments, we will work collegiately to ensure the successful delivery of the Joint Information Service Committee (Jisc) SafeShare project which could have broad impact across the UK scientific community and, at a regional level, work with the London AHSNs to create a TRE for research of local NHS data for London. This would be a big prize for the UK.

We are also proposing to launch a new Farr Institute Leadership programme, and Farr Institute Exchange Programme, providing the next generation of UK researchers mentorship and exposure to the brightest minds internationally. We are convinced that such a concerted effort is vital if the UK is to succeed in its quest to be the destination of choice for health data science.



*Poster Session, The Farr Institute International Conference 2015*



*The Farr Institute Directors, The Farr Institute International Conference 2015*



*Delegates at the Farr Institute International Conference 2015*



