**Table 1: Comparison of the UK Farr Institute and Health Data Research UK**

<table>
<thead>
<tr>
<th>Years of operation</th>
<th>Farr Institute (past)</th>
<th>HDR UK (present)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2013-2018</td>
<td>2018 + (15-year horizon)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Farr Institute (past)</th>
<th>HDR UK (present)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Galvanise UK research community With initial focus on record linkage</td>
<td>Directed science Direct data for health and healthcare: 6 themes: <a href="https://www.hdruk.ac.uk/research/">https://www.hdruk.ac.uk/research/</a></td>
</tr>
</tbody>
</table>

| Cross-centre peer reviewed science? | No | Yes. Activity matched funding to require cross Site science |

<table>
<thead>
<tr>
<th>Inter-disciplinarily</th>
<th>Farr Institute (past)</th>
<th>HDR UK (present)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Funding call focused on record linkage, epidemiology + health informatics</td>
<td>Greater inter-disciplinarily: more emphasis on understanding disease mechanism (e.g. with multi-omics), and more computer science /AI</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Funders</th>
<th>Farr Institute (past)</th>
<th>HDR UK (present)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10 including MRC, EPSRC, ESRC, NIHR, WT, BHF, CRUK, Arthritis Research UK, Scottish and Welsh Office.</td>
<td>9 as before + Northern Ireland (not CRUK, ARUK)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Initial funding</th>
<th>Farr Institute (past)</th>
<th>HDR UK (present)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£18m revenue (+£20m one off capital in 2013 + £1m network)</td>
<td>£110m revenue</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Structure and Governance</th>
<th>Farr Institute (past)</th>
<th>HDR UK (present)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Loose academic coalition 4 Directors: no formal Board or Executive</td>
<td>Company limited by guarantee 1 Director, Board, Executive</td>
</tr>
<tr>
<td>London (part)</td>
<td>University College London</td>
<td>Sites (co-ordinating research organisation) &amp;</td>
</tr>
<tr>
<td>Scotland</td>
<td>University of Dundee</td>
<td>Pan-London (University College London)</td>
</tr>
<tr>
<td>Wales</td>
<td>Swansea University</td>
<td>• Imperial, King’s and University College London</td>
</tr>
<tr>
<td>Manchester</td>
<td>University of Manchester</td>
<td>• London School of Hygiene &amp; Tropical Medicine</td>
</tr>
<tr>
<td>(full partners listed on map, Figure 1)</td>
<td></td>
<td>• Queen Mary University London</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Contractual agreements between Centres / Sites</th>
<th>Farr Institute (past)</th>
<th>HDR UK (present)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>None</td>
<td>Institute Agreement signed by co-ordinating research organisation in each Site and HDR UK</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Contractual agreements between co-ordinating research organisation and local partners</th>
<th>Farr Institute (past)</th>
<th>HDR UK (present)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>None</td>
<td>Institute Agreement signed by co-ordinating research organisation in each Site and HDR UK</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Location of central team</th>
<th>Farr Institute (past)</th>
<th>HDR UK (present)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Edinburgh</td>
<td>London</td>
</tr>
</tbody>
</table>
## Table 2. Central scientific challenge: EHR research at each stage of the translational cycle, illustrated by the 10 most highly cited research publications

<table>
<thead>
<tr>
<th>Theme</th>
<th>Advance</th>
<th>Potential impact</th>
<th>Reference</th>
<th>Citations (Google Scholar)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benefits of scale: High resolution epidemiology</td>
<td>Association of BMI with wide range of incidence cancers. Not previously reported at this scale (N=5m, primary care EHR not linked to HES data)</td>
<td>Prevention of cancer</td>
<td>Bhaskaran et al., Lancet 2014[17]</td>
<td>806</td>
</tr>
<tr>
<td>Benefits of scale: High resolution epidemiology</td>
<td>Association of blood pressure with wide range of incident cardiovascular diseases, beyond heart attack and stroke. Risk of 12 cardiovascular diseases not previously reported . N=1.9m, primary care data linked to HES CALIBER platform</td>
<td>Choice of endpoint in trials</td>
<td>Rapsomaniki et al., Lancet 2014[19]</td>
<td>695</td>
</tr>
<tr>
<td>Methods: transparent reporting</td>
<td>Reporting studies conducted using observational routinely collected health data (RECORD statement)</td>
<td>Reproducibility in science</td>
<td>Benchimol et al., PLoS Med 2015[41]</td>
<td></td>
</tr>
<tr>
<td>Nationwide evaluation of care and outcomes</td>
<td>International comparisons of whole health system data on acute myocardial infarction</td>
<td>NHS care</td>
<td>Chung et al., Lancet 2014[18]</td>
<td>220</td>
</tr>
<tr>
<td>Benefits of linkage: Methods</td>
<td>Linking 4 national structured data sources (CALIBER) for ascertaining and subtyping acute myocardial infarction: demonstrating quality of coding.</td>
<td>Quality of data</td>
<td>Herrett et al., BMJ 2013[43]</td>
<td>227</td>
</tr>
<tr>
<td>Primary care trials at point of care</td>
<td>Point of care randomised trials: 2 exemplars e Lung and RETROPRO</td>
<td>Capacity to mount trials</td>
<td>vanStaa et al., HTA 2014[45]</td>
<td>115</td>
</tr>
<tr>
<td>Healthcare</td>
<td>7 day working week and mortality using HES data and stroke registry</td>
<td>Junior doctors contracts</td>
<td>Freemantle et al., BMJ 2015[22] and Bray et al., Lancet 2016[46]</td>
<td>242</td>
</tr>
<tr>
<td>Genetic Discovery</td>
<td>Human knockouts First study of human knockouts among parentally related adults. First English study reporting linkage of primary care health records to genomic samples</td>
<td>Efficiency in drug development</td>
<td>Narasimhan et al., Science 2016[47]</td>
<td>136</td>
</tr>
</tbody>
</table>

Citation assessment performed 18th September 2019. EHR = Electronic Health Records, HES = Health Episode Statistics.
Table 3a. How this challenge is addressed: new national eInfrastructure platforms for accessing and sharing data

<table>
<thead>
<tr>
<th>Infrastructure/challenge</th>
<th>What was achieved?</th>
<th>References</th>
<th>What was the contribution of Farr</th>
<th>Evidence of impact and change 2013-2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK SECURE Eresearch PLATFORM (UKSeRP)</td>
<td>53 cohorts engaged covering 2m people: data from 21 cohorts covering 687,000 people available on website. The MRC’s Dementias Research Platform UK (DPUK) was the first major tenant with multiple UK cohorts. Other cohorts utilising UKSeRP are: UK Biobank (access to distributed outcome adjudication team), ALSPAC, AirWave and East London Genes for Health.</td>
<td>UKSeRP: Jones et al., Lancet 2016 [48]</td>
<td>Farr researchers created this key piece of national eInfrastructure.</td>
<td>50 applications for data; 25 approved and 11 underway. DPUK design informed similar models in US, Canada, Australia, South Korea. Platform extending research to other disease areas, e.g. stroke [<a href="https://www.dementiasplatform.uk/news/uk-wide-research-programme-to-investigate-dementia-in-stroke-patients">https://www.dementiasplatform.uk/news/uk-wide-research-programme-to-investigate-dementia-in-stroke-patients</a>][50] UKSeRP a key component to providing access to routine data and images in multiple bids in Life Sciences Industrial Strategy.</td>
</tr>
<tr>
<td>TRUSTED RESEARCH ENVIRONMENTS (TRE)</td>
<td>For the first time in the UK created ISO27001 accredited or Scottish Government accredited Safe Havens. 4 created: one per centre: SAIL HeRC TRE National Data Safe Haven (Scotland) CALIBER, London</td>
<td><a href="http://www.saildatabank.com">www.saildatabank.com</a> [51]</td>
<td>Farr researchers designed, built and operate the TReS. Financial resources for office accommodation and HPC computer; creation of a multidisciplinary environment (academic, informatics and NHS Staff). SAIL now a tenant on the robust UKSeRP infrastructure.</td>
<td>Our trusted research environments count a total of 2780 CPU cores and 3.0PB of storage, and a combined user base of in excess of 1000 researchers and in excess of 300 research projects completed or in flight. HeRC TRE provides capability for GM Connected Health City [<a href="http://www.connectedhealthcities.org">www.connectedhealthcities.org</a>] [55], Manchester BRC, DPUK sensing platform, MRC Clinical Proteomics Centre. Scotland: as whole, 131 live projects are underway, with access to records of 5.3 million people, and more than 200 dataset linkages made. Similar design underway in India and Brazil. Informed design of Digital Innovation Hubs in Life Sciences Industrial Strategy 2017.</td>
</tr>
<tr>
<td>CLOUD COMPUTE Multi-dimensional data requires scalable storage and compute capability</td>
<td>Shared infrastructure in off-site datacentre with over 9,000 cores and 4PB data. UCL, QMUL, LSHTM, Crick, Sanger, EBI, KCL and Farr London and Genomics England Award winning, at the time one of the largest private biomedical clouds in Europe.</td>
<td><a href="http://www.emedlab.ac.uk/">http://www.emedlab.ac.uk/</a> [56]</td>
<td>Farr researchers were core to the design and development of eMEDLAB, but it was funded by separate MRC award. The CLIMB infrastructure was designed and is managed by Farr investigator (Thompson).</td>
<td>eMedLab is a joint project with 6 institutions - UCL, QMUL, Crick, Sanger, KCL, EBI. The CLIMB project (Cloud Infrastructure for Microbial Bioinformatics) is a collaboration between Warwick, Birmingham, Cardiff, Swansea, Bath and Leicester Universities and The Quadram Institute Bioscience to develop and deploy a world leading cyber-infrastructure for microbial bioinformatics; providing free cloud-based compute, storage, and analysis tools for academic microbiologists in the UK.</td>
</tr>
<tr>
<td>JISC SAFE SHARE How to authorise researchers to remotely access and share data safely and securely, from their own project site – with information governance rules, varying with sensitivity of the data</td>
<td>A federated identity management system and a high assurance network overlay encrypted to National Cyber Security Centre (NCSC) standards.</td>
<td><a href="https://www.jisc.ac.uk/safe-share">https://www.jisc.ac.uk/safe-share</a> [58]</td>
<td>Farr researchers initiated the project with JISC and were involved in all stages of the project from requirements to evaluation of the service.</td>
<td>From the success of the Safe Share pilot project, JISC have added Safe Share to their service catalogue, providing service to ADRN and PSN users.</td>
</tr>
</tbody>
</table>
### Table 3b. How this challenge is addressed: Data made accessible in trusted research environments (data safe havens)*

<table>
<thead>
<tr>
<th>Datasets*</th>
<th>Linked primary-secondary care data</th>
<th>What was achieved?</th>
<th>Data safe haven and access procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Scotland NHS Data</strong></td>
<td>1.4m hospital admissions per year, 90m community prescriptions per year, plus other hospital activity data</td>
<td>No</td>
<td>450 live projects, with 130 accessing data. Multiple publications based on Scottish hospital data. NHS data taken into safe haven and prepared for research use. Quicker provisioning of data.</td>
</tr>
<tr>
<td><strong>Scotland NHS data: imaging</strong></td>
<td>a copy of all (1.5 m) historical images from the clinical NPACS into the Scottish Medical Imaging Database (SMI) on to the computing hardware at EPCC. ~1.5 million cases with an estimated total size of 81TB have been transferred.</td>
<td>No</td>
<td>An architectural solution and Irdmp prototype for handling big imaging data within a safe haven were designed and implemented. Currently being extended to run on the National Safe Haven hosted by Edinburgh Performance Computing Centre (EPCC) and to provide an anonymised extract from SMI for a small exemplar research project.</td>
</tr>
<tr>
<td><strong>Welsh NHS Data</strong></td>
<td>Includes: primary care, acute admissions, laboratory results, psychiatric admissions, maternity, Child health surveillance, Community prescribing, vital status (such as births, deaths, still births, etc.), cancer registry, wider societal data</td>
<td>Yes</td>
<td>Farr helped enhance SAIL with additional data sources, including to 86M rows of laboratory results, hospital dispensing data and fields derived from NLP of free text from clinical correspondence.</td>
</tr>
<tr>
<td><strong>English NHS Data</strong></td>
<td>Linking primary care (CPRD), hospital episode statistics, disease registry (acute myocardial infarction) and death registry with phenotyping and other tools on CALIBER platform</td>
<td>Yes</td>
<td>Farr delivered the secure remote access and developed the platform of methods and tools: used in over 50 publications by 20 research groups; internationally presented at NIH workshop on data science.</td>
</tr>
<tr>
<td><strong>Regional English NHS Data: detailed in-hospital data e.g. NIHR Health Informatics Collaborative Critical Care</strong></td>
<td>UCLH, King’s Imperial, Oxford, and Cambridge hospitals 40,000 unique admissions and 120 million data items</td>
<td>No</td>
<td>Farr provided Data Safe Haven, informatics expertise (Denaxas); first ever data sharing agreements and infrastructure to share data across 5 English NHS trusts. Datathon with US open data in critical care (MIMIC) Aboab et al., Science Translational Medicine 2016. [59]</td>
</tr>
<tr>
<td><strong>Regional English NHS Data: Greater Manchester HeRC Data Well Information Exchange</strong></td>
<td>linked primary secondary and social care data with capacity for linking to mobile and wearables</td>
<td>Yes</td>
<td>Coverage of a population of up to 2.8 million people</td>
</tr>
</tbody>
</table>

Note: * A complete list of EHR and administrative resources reported in Farr publications is provided in Supplementary Table 1
### Table 3c. How this challenge is addressed: EHR Phenotyping methods with structured and unstructured EHR data and wearables

<table>
<thead>
<tr>
<th>Challenge</th>
<th>What was achieved?</th>
<th>Reference</th>
<th>Farr contribution</th>
<th>Evidence of impact</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Structured data: defining EHR disease phenotypes</strong>&lt;br&gt;Phenotyping which are described by multiple EHR codes across primary and secondary care.&lt;br&gt;Poses challenges for replication and scale.</td>
<td>Developed an open platform of methods and tools (e.g. with semantic web technologies) for computable, reusable phenotypes of in primary care and secondary care data. Web-based repository of code lists, linked to publications, available to download. Software for the CALIBER research platform including tools to manage code lists and prepare electronic health record data for analysis.</td>
<td><a href="http://www.caliberresearch.co.uk">www.caliberresearch.co.uk</a></td>
<td>Dr Denaxas and Dr Shah have been a core members of the Farr team since 2013.</td>
<td>Internationally one of the largest open resources generating a ‘library’ of EHR disease phenotypes with &gt;70 complex diseases phenotyped papers using these tools highly cited.</td>
</tr>
<tr>
<td><strong>Identifying disease phenotypes</strong>&lt;br&gt;From high dimensional EHR codes.</td>
<td>Treated disease phenotyping as a problem of text categorization proposed a machine learning driven framework to automatically identify useful signals that define the condition.</td>
<td>Zhou et al. PLoS One[25]</td>
<td>Zhou and colleagues were members of the Farr CIPHER team.</td>
<td>The framework being applied to defining different conditions from EHRs and extended to unstructured data.</td>
</tr>
<tr>
<td><strong>Information about the same condition may be held in multiple EHR sources</strong></td>
<td>Linked 4 national structured data sources for ascertaining and sub-typing acute myocardial infarction. Linked data sources from England, Wales and Scotland. Includes extensive published code, algorithm, synthetic data github.com/RenalHDRUK</td>
<td>Herrett et al., BMJ 2013[43]</td>
<td>Black, Smeeht, Chess, Peek core members of Farr team since 2013; Project fully funded by Farr in 2017</td>
<td>Approach to definition and validation (clinical expert review; risk factors, prognostic and genetic) informing approaches in UK Biobank.</td>
</tr>
<tr>
<td><strong>Unstructured data</strong>&lt;br&gt;Mapping text to SNOMED-CT</td>
<td>National Research Data Appliance deployed in all health boards and trusts in Wales to facilitate data management, linkage and facilities for analysing free-text data using GATE software.</td>
<td>Fonterko-Shadrach et al., Seizure 2017[64]</td>
<td>Simon Thompson David Ford / Ronan Lyons</td>
<td>System now being extended to local authorities for ingestion of social services and other databases.</td>
</tr>
<tr>
<td><strong>Searching the entire hospital record</strong>&lt;br&gt;Structured and unstructured, in near real-time for alerting, research, trials and audit/coding</td>
<td>CogStack&amp;SemEHR Open source information retrieval and extraction platform implementing best-of-breed enterprise search, natural language processing (including semantic annotation), analytics and visualization technologies to unlock the health record and assist in clinical decision making and research.</td>
<td>Jackson et al., BMC Med Inform Decis Mak 2018[65]</td>
<td>Richard Dobson has been a member of the Farr team since 2015 (jointly with KCL)</td>
<td>Implemented in 3 London hospitals. Highlighted as key enabling infrastructure in CMO Generation Genome report Lasting impact on direct patient care through real time alerting, patient recruitment (eg to Genomics England, streamlining services (eg patient flow) and research through optional de-id step.</td>
</tr>
<tr>
<td><strong>Prescribing: to allow ‘synchronous’ prescribing</strong>&lt;br&gt;A natural language processing algorithm for converting text drug dosages to a set of structured fields (dose amount, units, frequency etc.) [1], which is published as an open source R package (<a href="http://caliberanalysis.r-forge.r-project.org/">http://caliberanalysis.r-forge.r-project.org/</a>)</td>
<td>published as an open source R package (<a href="http://caliberanalysis.r-forge.r-project.org/">http://caliberanalysis.r-forge.r-project.org/</a>)</td>
<td>Dr Shah has been a core member of the Farr team since 2013.</td>
<td>4.6 million patients in Vision systems. Being implemented in clinical practice for synchronizing prescriptions (Vision)</td>
<td></td>
</tr>
<tr>
<td><strong>Prescribing: to ACC coding</strong>&lt;br&gt;</td>
<td>Natural language processing to transform drug dosage instructions into quantification of drug exposure over time and connection to Anatomical Chemical Classification coding. The Prescribing Information System (PIS) holds over 1.6 billion prescriptions reimbursed in the community from January 1993 to 2014, with linkage to other health records data.</td>
<td>Alvarez-Madrazo et al., Int J Epilem 2016[67]</td>
<td>Part-funded by Farr</td>
<td>13 users. The PIS has preferred partner status for future pharmacovigilance in collaboration with the European Medicines Agency.</td>
</tr>
<tr>
<td><strong>Smartphones and wearables</strong>&lt;br&gt;Pervasive, continuous and objective remote monitoring through active and passive monitoring</td>
<td>Open source plug ’n’ play platform for mobile health enabling live monitoring through an extensible platform based on open data standards. Easily adapted for new disorders and devices. Initially developed as part of the IM2 RADAR-CNS programme. DPUK sensing platform.</td>
<td>RADAR-base.org Machin et al., International Journal of Population Data Science 2017[69]</td>
<td>Richard Dobson has been a member of the Farr team since 2015 (jointly with KCL)</td>
<td>Best of show winner at Bio-IT World 2018. Underpinning &gt;£80m of IM2 investments: RADAR-CNS RADAR-AD BigData@Heart AIMS-2-TRIALS Used in MRC Deep &amp; Frequent Phenotyping study.</td>
</tr>
<tr>
<td>Farr research</td>
<td>Clinical Guideline citing Farr research</td>
<td></td>
<td></td>
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<tr>
<td>---------------</td>
<td>----------------------------------------</td>
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<tr>
<td><strong>Complying with TB treatment</strong></td>
<td>World Health Organisation End TB Strategy 2017 Recommendation that Video Observed Therapy (VOT) is a method of supporting patients through tuberculosis treatment using remote observation of treatment with a smart phone app. [70]</td>
<td></td>
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<tr>
<td>Face to Face Directly Observed Treatment (DOT) which has been the mainstay of tuberculosis treatment for decades. The trial was stopped early due to overwhelming superiority of the intervention arm. Story et al., Lancet 2019 [70]</td>
<td>Commercial platform Sure/Adhere developed for Tuberculosis, HIV, Hepatitis C and Opioid Substitution Therapy and is beginning to be used in some high incidence countries. <a href="http://www.sureadhere.com/">http://www.sureadhere.com/</a></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Zoster vaccination</strong></td>
<td>UK Joint National Committee on Vaccination and Immunisation, and Centers for Disease Control and other international bodies have all cited this research informed decisions on introducing the zoster vaccine into routine practice. <a href="https://www.cdc.gov/vaccines/acip/recs/grade/herpes-zoster.html">https://www.cdc.gov/vaccines/acip/recs/grade/herpes-zoster.html</a> [71]</td>
<td></td>
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</tr>
<tr>
<td>Farr Institute led one of the very few UK analyses of US (Medicare) data, revealing that herpes zoster vaccination is associated with a reduction in post herpetic neuralgia (PHN) in routine clinical use. As PHN is the major complication of herpes zoster and is associated with highly significant morbidity and adverse impacts on quality of life, guidelines might recommend vaccination and substantial efforts are needed to increase vaccine use in routine care of elderly individuals. Langan et al., PLOS Med 2013 [44]</td>
<td><a href="http://www.who.int/immunization/sage/meetings/2014/april/2_Background_document_Herpes_Zoster.pdf">http://www.who.int/immunization/sage/meetings/2014/april/2_Background_document_Herpes_Zoster.pdf</a> [page 9] [72]</td>
<td></td>
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<td></td>
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<tr>
<td><strong>High Risk prescribing</strong></td>
<td>NHS Scotland National Therapeutic Indicators A number of the researchers’ high-risk prescribing indicators have been implemented, <a href="http://www.sehd.scot.nhs.uk/publications/DCC20151126etii_15-16_Full_Document_FINAL.pdf">http://www.sehd.scot.nhs.uk/publications/DCC20151126etii_15-16_Full_Document_FINAL.pdf</a> in NHS prescribing data analysis tools, and e.g. NHS Forth Valley stopped high-risk medicines in 1,200 patients as a result [74]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Farr Institute research has informed a number high-risk prescribing indicators Marwick et al., BMJ QualSaf. 2014. [73]</td>
<td>Farr Institute led the only collaboration with AstraZeneca demonstrating generalisability of the trial population to unselected patients surviving an acute myocardial infarction: event rates of safety and benefits Timmis et al., BMJ 2016. [80]</td>
<td></td>
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<tr>
<td>Farr investigators analysed 71,551 women using Human Fertilisation and Embryology Authority (HFEA) national database. Most couples in the UK still do not receive 3 IVF cycles; around 83% of women receiving IVF would achieve a live birth by 8th complete cycle, similar to the natural live birth rate in a non-contraception practising population. McLernon et al., Hum Reprod. 2016 [75]</td>
<td>NHS Scotland Cited in the Scottish Government National Infertility Group Report where it contributed evidence which led to the recommendation, and subsequent policy change, of increasing the number of NHS funded complete cycles of IVF in Scotland from two to three. Results support the call from NICE to develop consistent IVF policies based on three complete cycles. [<a href="http://www.gov.scot/Resource/0050/00501403.pdf">http://www.gov.scot/Resource/0050/00501403.pdf</a>] [76]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Migrant health</strong></td>
<td>European Society of Cardiology (ESC). 2016 ESC Guidelines for the management of atrial fibrillation developed in collaboration with EACTS. The Task Force for the management of atrial fibrillation of European Society of Cardiology (ESC). 2016 ESC Guidelines for the management of atrial fibrillation developed in collaboration with EACTS.</td>
<td></td>
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<tr>
<td>Farr Institute led the development and validated a novel probabilistic data linkage method to create a cohort of over half a million migrants demonstrating that the majority of cases diagnosed in the UK were likely to have resulted from latent infection and made the case for extending screening periods Aldridge et al., Lancet 2016. [77]</td>
<td>American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines 2017 Guideline for the Prevention, Detection, Evaluation, and Management of High Blood Pressure in Adults: Executive Summary. [<a href="https://www.acc.org/~/media/Non-Clinical/Files-PDFs-Excel-MS-Word-etc/Guidelines/2017/Guidelines_Made_Simple_2017_HBP.pdf">https://www.acc.org/~/media/Non-Clinical/Files-PDFs-Excel-MS-Word-etc/Guidelines/2017/Guidelines_Made_Simple_2017_HBP.pdf</a>] [78]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hypertension</strong></td>
<td>NICE. Ticagrelor for preventing atherothrombotic events after myocardial infarction. Technology appraisal guidance [TA420]. Published 14 December 2016 [<a href="https://www.nice.org.uk/guidance/TA420/chapter/1-Recommendations">https://www.nice.org.uk/guidance/TA420/chapter/1-Recommendations</a>] [81]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Atrial fibrillation</strong></td>
<td></td>
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</tr>
<tr>
<td>Farr Institute led the only analysis to report separately in women and men the threshold at which there are net benefits of treating atrial fibrillation with oral anticoagulants. Allan et al., Heart 2016 [79]</td>
<td>World Health Organisation End TB Strategy 2017 Recommendation that Video Observed Therapy (VOT) is a method of supporting patients through tuberculosis treatment using remote observation of treatment with a smart phone app. [70]</td>
<td></td>
<td></td>
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<tr>
<td><strong>Stable coronary disease</strong></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Farr Institute led a collaboration with Astra Zeneca demonstrating generalisability of the trial population to unselected patients surviving an acute myocardial infarction: event rates of safety and benefits Timmis et al., BMJ 2016. [80]</td>
<td>Commercial platform Sure/Adhere developed for Tuberculosis, HIV, Hepatitis C and Opioid Substitution Therapy and is beginning to be used in some high incidence countries. <a href="http://www.sureadhere.com/">http://www.sureadhere.com/</a></td>
<td></td>
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</tr>
<tr>
<td><strong>Genomic medicine</strong></td>
<td></td>
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</tr>
<tr>
<td>Farr Institute research was cited in the report highlighting importance of longitudinal NHS EHR phenotyping data in delivering vision of genomic medicine. Wu et al., JAMIA 2018 [66]</td>
<td>Chief Medical Officer Annual Report ‘Generation Genome’ the government has established the National Genomics Board chaired by the health minister, to implement recommendations</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
Table 4. Change in UK training opportunities in data science and health informatics between 2013 and 2018

<table>
<thead>
<tr>
<th>Level / University</th>
<th>Course title</th>
<th>Year established</th>
<th>Number of students/delegates 2013-2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Masters level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UCL</td>
<td>Health Informatics</td>
<td>1999</td>
<td>170</td>
</tr>
<tr>
<td>UCL</td>
<td>Health Data Science for Research in Biomedicine</td>
<td>2015</td>
<td>74</td>
</tr>
<tr>
<td>UCL</td>
<td>Health Data Analytics</td>
<td>2017</td>
<td>36</td>
</tr>
<tr>
<td>Swansea University</td>
<td>Health Informatics</td>
<td>2001</td>
<td>176</td>
</tr>
<tr>
<td>Swansea University</td>
<td>Health Data Science</td>
<td>2014</td>
<td>88</td>
</tr>
<tr>
<td>Manchester University</td>
<td>Health Data Science</td>
<td>2014</td>
<td>60</td>
</tr>
<tr>
<td>Short courses</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UCL</td>
<td>Farr Institute London 13 short courses (1-3 days)</td>
<td>2014</td>
<td>684</td>
</tr>
<tr>
<td>Swansea University</td>
<td>Analysis of linked health data</td>
<td>2008</td>
<td>335</td>
</tr>
<tr>
<td>Manchester University</td>
<td>Informatics for Healthcare Systems: Improving Skills for Patient Driven Healthcare</td>
<td>2011</td>
<td>332</td>
</tr>
<tr>
<td>Leadership</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Edinburgh University / Imperial College*</td>
<td>NHS Digital Academy</td>
<td>2018</td>
<td>105</td>
</tr>
<tr>
<td>All 4 Farr Centres: residential meetings in Manchester, Swansea</td>
<td>UK Farr Future Leaders Course</td>
<td>2017</td>
<td>42</td>
</tr>
</tbody>
</table>

*Offered at MSc/Postgraduate Diploma or Postgraduate Certificate levels

†Postgraduate Diploma of Digital Health Leadership
### Supplementary Table 1: EHR and administrative data sources reported in the 100 Farr Institute publications

<table>
<thead>
<tr>
<th>Setting of denominator population / Data Sources</th>
<th>Publication Using the Named Data Sources*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PRIMARY CARE</strong></td>
<td>Rapsomaniki et al., Lancet, 2014, PMID: 24881994</td>
</tr>
<tr>
<td>Clinical research using Linked Bespoke studies and Electronic health Records (CALIBER)*</td>
<td>Bhaskaran et al., Lancet, 2014, PMID: 25129328</td>
</tr>
<tr>
<td>UK Clinical Practice Research Datalink (CPRD)</td>
<td>Aldridge et al., PLoS One, 2016, PMID: 26933880</td>
</tr>
<tr>
<td>General practice data (Scotland)</td>
<td>Brophy et al., Am J Gastroenterol, 2013, PMID: 23582838</td>
</tr>
<tr>
<td>General practice records (in Secure Anonymised Information Linkage database [SAIL])</td>
<td>Lyons et al., J Epid Comm Health, 2016, PMID: 27217535</td>
</tr>
<tr>
<td>Prescribing Information System (PIS, for Scotland)</td>
<td>Busby et al., Int J Cancer, 2017, PMID: 28120338</td>
</tr>
<tr>
<td>Primary Care Clinical Information Unit Research database (PCCIUR)</td>
<td>Paranjoty et al., Lancet, 2018, PMID: 24249824</td>
</tr>
<tr>
<td>Wales Demographic Service Dataset (WDS)</td>
<td>Morgan et al., PLoS One, 2013, PMID: 24236140</td>
</tr>
<tr>
<td>Wales Electronic Cohort for Children (WECC, in SAIL)</td>
<td>Hutchings et al., Peditrics, 2016, PMID: 23940801</td>
</tr>
<tr>
<td>WECC(4)*</td>
<td>Paranjoty et al., Peditrics, 2013, PMID: 24249824</td>
</tr>
<tr>
<td>WECC(S)</td>
<td>Hutchings et al., PLoS One, 2013, PMID: 23940801</td>
</tr>
<tr>
<td><strong>HOSPITAL (DETAILED DATA)</strong></td>
<td></td>
</tr>
<tr>
<td>Aberdeen Maternity and Neonatal Databank (AMND)</td>
<td>Clemens et al., Environ Int, 2017, PMID: 28753483</td>
</tr>
<tr>
<td>Antenatal care (Wales)</td>
<td>Hurt et al., Prenat Diagn, 2015, PMID: 26475362</td>
</tr>
<tr>
<td>Clinical Record Interactive Search (CRIS)</td>
<td>Iqbal et al., PLoS One, 2015, PMID: 26273830</td>
</tr>
<tr>
<td>Genetic service laboratories (Scotland)</td>
<td>Jacobs et al., PLoS One, 2016., PMID: 27907018</td>
</tr>
<tr>
<td>Intensive Care National Audit &amp; Research Centre data</td>
<td>Mukherjee et al., BMC Med, 2016, PMID: 27568881</td>
</tr>
<tr>
<td>Medicare (United States)</td>
<td>Langan et al., PLoS Med, 2013, PMID: 23555738</td>
</tr>
<tr>
<td>Paediatric Intensive Care Audit Network (PICANet)</td>
<td>Gilbert et al., Lancet, 2016, PMID: 26946925</td>
</tr>
<tr>
<td><strong>HOSPITAL (LIMITED CODED DATA)</strong></td>
<td></td>
</tr>
<tr>
<td>A&amp;E Datamart</td>
<td>Mukherjee et al., BMC Med, 2016, PMID: 27568881</td>
</tr>
<tr>
<td>A&amp;E2 database</td>
<td>Mole et al., BMJ Open, 2016, PMID: 27311912</td>
</tr>
<tr>
<td>Adult ICU data (Cambridge; Guy's, King's and St Thomas', Imperial, Oxford and UCL)</td>
<td>Harris et al., Int J Med Insors, 2018, PMID: 29500026</td>
</tr>
<tr>
<td>Emergency Department Dataset (in SAIL)</td>
<td>Mukherjee et al., BMC Med, 2016, PMID: 27568881</td>
</tr>
<tr>
<td>Hospital data (Oman Princess of Wales Hospital; Scunthorpe General Hospital; Scarborough Hospital; and York Hospital)</td>
<td>Mohammed et al., J Health Serv Res Pol, 2017, PMID: 29940165</td>
</tr>
<tr>
<td>Hospital data (Denmark)</td>
<td>Schmidt et al., Am J Epidemiol, 2018, PMID: 29053820</td>
</tr>
<tr>
<td>Hospital Episode Statistics (HES)</td>
<td>Herbert et al., PLoS Med, 2015, PMID: 26714280</td>
</tr>
<tr>
<td>Maternity record data (Manchester)</td>
<td>Kelly et al., Autism, 2017, PMID: 29113453</td>
</tr>
<tr>
<td>Out-patient datasets (in SAIL)</td>
<td>Brophy et al., Am J Gastroenterol, 2013, PMID: 23582838</td>
</tr>
<tr>
<td>Patient Episode Database for Wales (PEDW, in SAIL)</td>
<td>Morgan et al., BMJ open, 2014, PMID: 24236140</td>
</tr>
<tr>
<td>Scottish Morbidity Record 00 (Outpatient Attendance)</td>
<td>Mole et al., BMJ Open, 2016, PMID: 27311912</td>
</tr>
<tr>
<td>Scottish Morbidity Record 01 (General/Acute Inpatient and Day Case data set)</td>
<td>Black et al., PLoS Med, 2016, PMID: 26978456</td>
</tr>
<tr>
<td>Scottish Morbidity Record 02 (Maternity Inpatient and Day Case)</td>
<td>Black et al., PLoS Med, 2016, PMID: 26978456</td>
</tr>
<tr>
<td>Scottish Morbidity Record 04 (Mental Health Inpatient and Day Case)</td>
<td>Mole et al., BMJ Open, 2016, PMID: 27311912</td>
</tr>
<tr>
<td>Ultrasound scan (a Welsh NHS hospital)</td>
<td>Hurt et al., Prenat Diagn, 2015, PMID: 26475362</td>
</tr>
<tr>
<td><strong>registries of diseases and procedures</strong></td>
<td></td>
</tr>
<tr>
<td>British Cardiovascular Intervention Society database (BCIS)</td>
<td>Hulme et al., CircCardiovascInterv, 2017, PMID: 28196898</td>
</tr>
<tr>
<td>Danish National Diabetes Register (NDR)</td>
<td>Schmidt et al., Am J Epidemiol, 2018, PMID: 29053820</td>
</tr>
<tr>
<td>Danish National Patient Registry</td>
<td>Schmidt et al., Am J Epidemiol, 2018, PMID: 29053820</td>
</tr>
<tr>
<td>Danish National Prescription Registry</td>
<td>Schmidt et al., Am J Epidemiol, 2018, PMID: 29053820</td>
</tr>
<tr>
<td>Myocardial Ischaemia National Audit Project (MINAP)</td>
<td>Chung et al., Lancet, 2014, PMID: 24461715</td>
</tr>
<tr>
<td>National Adult Cardiac Surgery Audit (NACSA)*</td>
<td>Hickey et al., JAMA Intern Med, 2017, PMID: 27820610</td>
</tr>
<tr>
<td>Psychiatric Central Research Register (PCRr)</td>
<td>Schmidt et al., Am J Epidemiol, 2018, PMID: 29053820</td>
</tr>
<tr>
<td>Renal management system (from NHS Grampian)</td>
<td>Marks et al., Nephrol Dial Transplant, 2015, PMID: 25943597</td>
</tr>
<tr>
<td>Respiratory Datamart data</td>
<td>Aldridge et al., PLoS One, 2016, PMID: 26933880</td>
</tr>
<tr>
<td>Scottish Intensive Care Society Audit Group (SCISAG)</td>
<td>Mole et al., BMJ Open, 2016, PMID: 27311912</td>
</tr>
<tr>
<td>Scottish Morbidity Record 06 (Scottish Cancer Registry)</td>
<td>Black et al., PLoS Med, 2016, PMID: 26978456</td>
</tr>
<tr>
<td>Scottish Renal Registry (SRR)</td>
<td>Marks et al., Nephrol Dial Transplant, 2015, PMID: 25943597</td>
</tr>
<tr>
<td>Scottish Stroke Care Audit (SSCA)</td>
<td>Turner et al., J Neurol Neurosurg Psyc, 2015, PMID: 24966391</td>
</tr>
</tbody>
</table>
Setting of denominator population / Data Sources

Sentinel Stroke National Audit Programme (SSNAP)  
Swedish Web-System for Enhancement and Development of Evidence-Based Care in Heart Disease Evaluated According to Recommended Therapies / Register of Information and Knowledge about Swedish Heart Intensive care Admissions (SWEDEHEART/RIKSHTA)  
United Kingdom Human Fertilisation and Embryology Authority (HFEA)  
National Data Bank for Rheumatic Diseases (United States)  

DEATH DATA

Death certification records (from the CATCH trial)  
Mortality data (in SAIL)  
National Death Registry (Sweden)  
Office for National Statistics (ONS) data  
Scottish Health and Ethnicity Linkage Study (SHELS)  
Scottish Morbidity Record 99 (Death Registrations)

OTHER HEALTH

All Wales Injury Surveillance System (AWISS)  
Caerphilly County Borough Council (Wales)  
Electronic Communication of Surveillance in Scotland (ECOSS)  
Enhanced Tuberculosis Surveillance system (ETS)  
Health and Occupation Research Network  
Health Intelligence (from NHS Grampian)  
National Community Child Health Database (NCCHD)  
NHS-24  
Practice Team Information (PTI)  
Salford Integrated Record (SIR)  
Scottish Care Information (SCI) Stores  
Support Needs System (SNS)  

SOCIO-ECONOMIC AND ENVIRONMENT

Demographic data (from NHS Scotland)  
General Register Office (GRO, for Scotland) data  
National Records of Scotland (NRS) data  
Northern Ireland Statistics data  
Annual pupil census (Scotland)  
Child Health Systems Programme (CHSP) School  
Danish Population Education Register (PER)  
Education records (in SAIL)  
School attainment record (Scotland)

Air pollution data  
Local weather data  
United Kingdom Atomic Energy Authority (AEA)  
United Kingdom Department for the Environment, Food and Rural Affairs (DEFRA) data  
Department of Work and Pensions (DWP) data  
Index of Multiple Deprivation (IMD)  
Weekly Returns Service (WRS)  
Welsh Costing Return (WCR)  
Administrative data (crime rate from the Scottish Longitudinal Study [SLS] study)  
Global Positioning System (for smartphone)  
Census data (from the SLS study)  
Department for Social Development data (Northern Ireland)  
Department of Finance and Personnel data (Northern Ireland)  
Department of Health Social Service and Public Safety data (Northern Ireland)  
International Organization for Migration database (ROM) data  
Swansea Social Services data  
Tweets

Notes: Multiple datasets are reported together in h: CALIBER [4]: CPRD, HES, MINAP, ONS mortality and index of multiple deprivation c. WECC [4]: the Welsh Demographic Service (WDS), the National Community and Child Health Database (NCCHD); the Office for National Statistics (ONS), the Patient Episode Database for Wales (PEDW); d. WECC [6]: Public Health Birth files from the Office for National Statistics, National Community Child Health Database, Public Health Mortality files from the Office for National Statistics, Patient Episode Dataset for Wales, All Wales Perinatal Survey, Congenital Anomaly Register and Information Service; e. WECC [8]: General Practice data, the Welsh Demographic Service (WDS), the National Community and Child Health Database (NCCHD), the Office for National Statistics (ONS), the Patient Episode Database for Wales (PEDW), the Congenital Anomaly Register and Information Services (CARIS), the National Pupil Database (NPD), the Pupil Level Annual School Census (PLASC); f. NACSA [3]: Life status, surgical
reoperation, and Transcatheter Aortic Valve Implantation (TAVI); g. SHELS [2]: death records (Scotland), 2001 census records (Scotland); h. AWISS [3]: emergency department attendances, general practice events, and hospital admissions; SIR [2]: data from 53 primary care providers and 1 secondary care provider.

**Supplementary Figure 1: Farr Institute allocation of the £18m revenue, £20m capital and £1m network**

![Supplementary Figure 1: Farr Institute allocation of the £18m revenue, £20m capital and £1m network](image-url)
Supplementary Figure 2: Timeline: evolution from 4 separate centres to Farr as a single national institute
Supplementary Figure 3: Timeline: information governance scandals and policy context shaping evolution of Farr
Supplementary Figure 4: Attribution of research publications to the Farr Institute
Supplementary Figure 5: Change in inter-disciplinarity based on departmental affiliations: first 30 months and final 30 months
Supplementary Figure 6: Number of institutions collaborating per publication* over time

* Based on those Farr 100 publications with a record in Scopus (n=87) allowing unique identification of institutions.
Supplementary Box: Original funding call from the UK Medical Research Council (2011) which led to the establishment of the Farr Institute

E-Health Informatics Research Centres (E-HIRCs) Call

It is vital that the UK research community is in a strong position to maximise the health research potential offered by linking electronic health records with other forms of routinely collected data and research datasets. The major funders of health research are working in partnership to ensure the UK builds critical mass and expertise in health informatics research. This call to establish centres of excellence in research using e-health records is part of a shared vision to promote linkage of electronic data for research.

Aim of the Call

The Medical Research Council, in partnership with Arthritis Research UK, the British Heart Foundation, Cancer Research UK, the Economic and Social Research Council, the Engineering and Physical Sciences Research Council, the National Institute of Health Research, the National Institute for Social Care and Health Research (Welsh Assembly Government), the Chief Scientist Office (Scottish Government Health Directorates) and the Wellcome Trust invite proposals for Centres of Excellence in research linking electronic health data. The Centres will pursue cutting-edge research, deliver innovative linkage and analysis of health-related data sets, build research capacity and expertise and act as an interface with industry, practice and policy with the aim of building and sustaining a vibrant health informatics research capability in the UK.

Background

The UK has an international reputation for undertaking leading edge large scale health data analysis and population based research. New infrastructure initiatives across the UK, designed to make electronic health records available for research purposes in a secure and ethical environment, will provide unprecedented opportunities for clinical, health services, social and public health research. In recognition of the vast research potential offered by e-health records, the major funders of e-health records research came together under the Office for Strategic Coordination of Health Research (OSCHR) to develop an e-health Research Framework. To understand how well the UK was placed to capitalise on these opportunities, the MRC led a mapping exercise on behalf of the UK research funders and the Association of British Pharmaceutical Industries (ABPI) to review the existing UK capability and examine the requirements to support a

1 The NIHR Research Capability Programme in England, the Scottish Health Informatics Programme (SHIP) and the Welsh Secure Anonymised Information Linkage system (SAIL)
2 Cancer Research UK (CRUK), Chief Scientist Office, Scottish Government Health Directorates (CSO), Engineering and Physical Sciences Research Council (EPSRC), Economic and Social Research Council (ESRC), Medical Research Council (MRC), National Institute for Health Research (NIHR), National Institute for Social Care and Health Research (NISCHR), The Wellcome Trust
3 http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC006669
4 Http://www.mrc.ac.uk/e-health
sustainable research base in the future\textsuperscript{5}. The report highlighted the need to build capability and capacity in health informatics research and for further methodological development in complex data linkage.

The wealth of scientific possibilities and huge benefits for biomedical and social sciences offered by data linkage were further highlighted at a recent Frontiers meeting hosted by the funders\textsuperscript{6}. In response to these inputs the funders have agreed to jointly fund a number of centres of excellence in health informatics research across the UK with the aim of conducting leading research and building capacity in the area.

**Expectations of Centres**

The objectives of the Centres will be to:

- provide a focus for high-quality, cutting-edge research using electronic health records;
- undertake and promote innovative linkage and analysis of large health related data sets including social and economic data;
- build capacity in electronic health informatics research.

Centres will either be based around an existing research group(s) or research unit(s) in a single institution or bring together expertise across several institutes in a wider consortium. By building on existing research strengths, Centres will be well placed to provide UK leadership in the area. Centres will create UK capability in electronic health informatics research by providing advice and expertise to support the wider research community, encouraging collaboration across the biomedical, social and computer sciences and offering training and career development opportunities.

Centres will focus on research to improve the health and wellbeing of the population or address major challenges arising from conditions of significant health burden such as cancer, cardiovascular disease, musculoskeletal conditions, neurodegeneration and mental health.

*Each Centre must meet the following **ESSENTIAL** criteria:*

**Scientific Excellence**

- Existing strengths in health-related informatics research in a recognised research environment; and
- Innovative programmes of research which involve linkage between electronic health records or linkage of electronic health records to other datasets including research data, geo-spatial and socio-economic records. Use of existing or emerging e-health records infrastructures must be core to research activities; and
- Develop and apply new methods for data manipulation, linkage or analysis in key areas of statistics, computer science or informatics.

**Training and career development**

\textsuperscript{5} Http://www.mrc.ac.uk/e-health
\textsuperscript{6} Wellcome, ESRC and MRC
• Offer training for PhD students, post-doctoral fellows and visiting workers where skills can be learnt on the job; and
• Provide career development opportunities for enabling roles such as data managers, software engineers, informaticians and data analysts; and
• Create an environment to develop and sustain capacity in research using e-health records.

Management structures and Governance
• Each Centre will have a Director based within the lead host institution who will take responsibility for the delivery of the objectives of the Centre.
• The Director will be a recognised leader in health informatics research.
• Centres must have a clear governance structure with well articulated decision making processes.
• Senior management roles and responsibilities must be clear.

Networking activities
• Provide scientific leadership, support and advice to the wider research community on the design, linkage, conduct and analysis of e-health related research.
• Contribute to networking activities with the other e-health research Centres of excellence designed to strengthen the national capability in e-health records research.

Public engagement
Centres must engage patients and the public individually or collectively in research and undertake a programme of activities to promote public and professional understanding of the health and societal benefits of e-health records research.

All Centres will be required to demonstrate they meet the essential criteria but it is recognised that individual Centres may not have equal strengths in each of the criteria.

Additional Strengths
In addition to meeting the essential criteria the funders welcome applications which address any of the following:

• Establish a modular training programme in e-health records research that would assist individuals from different backgrounds to ‘top up’ their skills.
• Issues relating to ethics, security, anonymisation and governance surrounding data linkage.
• Develop innovative linkage across different types of data such as omics and imaging data, and other non-health datasets including demographic, geo-spatial and socio-economic data.
• Translate research outputs by developing effective links with the NHS, policy makers, the public and industry including secondments and temporary placements and ‘case type awards’.
• Create and provide access to datasets for secondary analysis by the research community where legally and ethically possible.

Sustainability
In line with the funders’ desire to build long term capability in e-health informatics research in the UK, Centres will be required to demonstrate commitment from the host HEI(s) to maintain the capacity and expertise developed by the Centre, both in academic and enabling ‘non-academic’ positions, beyond the term of the five year Centre award. A supporting statement including a sustainability plan from the host institution(s) will be required (from the Vice Chancellor or equivalent).

A UK network of E-HIRCs
Individual Centres will be networked together to further strengthen the national capability for using electronic health data in research. The UK network of E-HIRCs will facilitate information exchange about research opportunities and best practice including consideration of ethics and governance issues. The Network will provide a focus for networking with the wider research community and encourage cross-Centre collaborative working. Each Centre will be expected to collaborate on coordinating workshops, seminars, web-based resources, etc to ensure the UK at the leading edge of the field.

Collectively the UK network of E-HIRCs will accelerate the translational process through the development of innovative and transformative approaches for the linkage of data, as well as the design, conduct and analysis of research using electronic health records.

Once the Centres are awarded, a nominated ‘lead’ centre will be allocated a budget in the vicinity of £1m to coordinate activities. Applicants can bid in their proposals to undertake this role.

Funding available
Funds of ~£15m are available to support a number of Centres across the UK for up to five-years and awards will be made on the basis of full economic costs (fEC) at approximately 67% to reflect collaborative funding from research councils, charities and government departments. As these Centres will represent leading foci of expertise it is expected that requests for support will be for a minimum of £3m over the funding period, although less may be awarded as determined by rigorous peer-review. In all areas, the resources requested must be fully justified as part of a coherent scientific programme; the quality of the science proposed will be key.

Following completion of the five year period, a funding extension that tapers over the next 5 years may be considered if good progress has been made. However a long term sustainability plan with demonstrable commitment by the host HEI to ongoing support of the Centre at the end of the initial 5 year funding term must be part of the Centre application.
Awards for Centres will be managed by the MRC on behalf of the partners and subject to MRC terms and conditions.

Support available

- The Director’s salary costs for the portion of their time dedicated to scientific and management leadership of the Centre;
- Funds for research, in particular to support new collaborations across and outside the Centre, although it is anticipated that most of the research in any Centre will be supported by successful applications to response mode competitions.
- Funds to enable the Centre to function as a cohesive regional or UK focus for e-health research (e.g. funds for pilot studies, support posts, networking costs, common resources/datasets and equipment etc);
- Start-up costs for new positions to develop capacity (this can include the initial costs of new appointments from overseas) or key positions central to the Centre’s success;
- Funds to provide a support/advisory service to collaborate with researchers working outside the Centre wishing to use electronic health care records for research;
- Funds for training and capacity building in methodologies underpinning linking and the use of electronic health records. Centres are eligible for MSc and PhD studentships in areas were unmet need is clearly articulated.
- Dedicated Centre management and administrative staff
- Other resources essential to establish and maintain the Centre;
- Public and user engagement, coordination and collaboration costs to bring the research closer to the patient or to application.
- Translational activities for building collaborations with industry, NHS, etc
- Resources to undertake activities as part of the wider UK network. If wishing to take the lead, a request for a coordinator can be made.

Support not available

Funds cannot be requested for capital and refurbishment costs or infrastructure and core administrative services (secretarial, finance, personnel, computing support, estates and building maintenance) covered by the indirect cost component of FEC.

New activities and facilities will only be funded where they are clearly not attributable to existing grants. The funding partnership will not provide support for any shared infrastructure.

Eligibility

For administrative purposes, the E-HIRC application will be led by a single UK academic institution or academic analogue approved by the Research Councils.

7 [http://www.rcuk.ac.uk/research/Pages/Eligibilityforrcs.aspx](http://www.rcuk.ac.uk/research/Pages/Eligibilityforrcs.aspx)
Only one proposal is permitted per applying host institution. Bids involving multiple sites are welcomed but will be required to demonstrate the added value of the consortium arrangement and how effective working across sites will be achieved. Applications throughout the UK are eligible.

The Director must be the principal investigator on the proposal and be given appropriate status within the lead host institution. The Director should be in a position to influence research programmes associated with the Centre, and must have full control over use of Centre Grant funds.

Co-applicants are expected to be the leading scientists involved in delivering the Centre’s aims and objectives.

The normal MRC eligibility rules apply; please see the applicants’ handbook and the Research Council UK website.

Partnerships with industry are welcome. Applicants considering establishing a collaboration with an industrial partner(s), are advised to refer to the guidance on MRC Industry Collaboration Awards (MICAs).

Application and assessment process

Applicants will submit outline proposals on the RCUK Je-s application system. Specific instructions for completing the case for support are detailed in the Guidance Notes for e-Health Informatics Research Centres [insert link]. Outline proposals will be reviewed by an expert Scientific Panel and successful bids will be invited to submit full proposals. The panel will encourage collaboration across bids where appropriate. Full proposals will be externally peer reviewed before being considered by the Scientific Panel. Applicants will be required to present their application to the Panel before a final recommendation for funding is made. Final funding decisions will be made by the contributing funding partners.

The Host Institution(s) will be expected to identify their own targets and milestones for the Centre and report to funders on an annual basis. Centres will also be required to annually submit reports to MRC’s Electronic Valuation System (e-Val).

ALL applicants are required to discuss their proposals with the Programme Manager before submission. A brief abstract should be e-mailed in advance of discussions.

Programme Manager:

<table>
<thead>
<tr>
<th>Dr Mark Pitman</th>
</tr>
</thead>
<tbody>
<tr>
<td>E-Mail: <a href="mailto:mark.pitman@headoffice.mrc.ac.uk">mark.pitman@headoffice.mrc.ac.uk</a></td>
</tr>
<tr>
<td>Tel: 0207 395 2215</td>
</tr>
</tbody>
</table>
## Timetable

<table>
<thead>
<tr>
<th>Task</th>
<th>Deadline</th>
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<tbody>
<tr>
<td>Call Launch</td>
<td>6th September 2011</td>
</tr>
<tr>
<td>Deadline of Outline Applications</td>
<td>1st November 2011</td>
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<tr>
<td>Panel Meeting (Outlines)</td>
<td>9th December 2011</td>
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<tr>
<td>Deadline of Full Applications</td>
<td>27th February 2012</td>
</tr>
<tr>
<td>Scientific Panel meeting with interviews</td>
<td>June 2012</td>
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</table>
A national initiative in data science for health: an evaluation of the UK Farr Institute
Acknowledgements
The funders of the Farr Institute were: Medical Research Council (co-ordinating), Arthritis Research UK, British Heart Foundation, Cancer Research UK, Chief Scientist Office, Economic and Social Research Council, Engineering and Physical Sciences Research Council, National Institute for Health Research, National Institute for Social Care and Health Research, and Wellcome Trust.

Farr Institute
The work of the Farr Institute was carried out by a network of about 430 investigators, students and professional support staff: the majority of whom received either no, or limited direct funding support from the Farr Institute award for their salaries, as follows:

International Advisory Board
Nancy Pedersen (Chair), Professor in Genetic Epidemiology, Department of Medical Epidemiology and Biostatistics, Karolinska Institute, Sweden, Director of LifeGene project
Dan Roden, Assistant Vice Chancellor for Personalized Medicine Vanderbilt University Medical Center
Phil Burstein, Vice President, Health Care Data Optimisation and Data Stewardship Operation, Drug Development Sciences, GlaxoSmithKline
Georges De Moor, Immediate Past President and Member of the Board of European Institute for Health Records and Head of the Department of Medical Informatics and Statistics at the State University of Ghent, Belgium
Ian Crichton, Managing Director UK Health Business, Serco
Simon Denegri, Chair of INVOLVE and NIHR’s National Director for Public Participation and Engagement in Research
Isaac Kohane, Professor of Pediatrics and Health Sciences and Technology, Harvard Medical School, Chair, Informatics Program, Boston Children’s Hospital, Children’s Hospital Informatics Program (CHIP)
William Lowrance, Consultant in Health Research Ethics & Policy, La Grande Motte France, and author of Privacy and Confidentiality in Health Research
Michael Parker, Professor of Bioethics and Director of the Ethox Centre, University of Oxford
John Speakman, Senior Director, Research Information Technology, NYU Langone Medical Center
Graham Spittle, Chief Technology Officer Europe & Vice President, Software Group, IBM
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**Research investigators (not listed above), nearly all of whom held substantive academic appointments in universities (funded 0.02 WTE)**  
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Ann Blandford, Professor of Human Computer Interaction, University College London  
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Paul Burton, Professor of Infrastructural Epidemiology, University of Bristol  
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Adam Panagiotopoulos, Research Assistant, Edinburgh Law School
Vaclav Papez, Research Associate, University College London
New tenured academic appointments, leveraging the Farr Institute award

Robert Aldridge, Wellcome Trust Clinical Research Career Development Fellow and Consultant in Public Health, University College London
Samantha Alvarez-Madrazo, Research Associate, University of Strathclyde
Athanasios Anastasiou, Lecturer in Health Data Science, Swansea University Medical School, Swansea University

New tenured academic appointments, leveraging the Farr Institute award

Robert Aldridge, Wellcome Trust Clinical Research Career Development Fellow and Consultant in Public Health, University College London
Samantha Alvarez-Madrazo, Research Associate, University of Strathclyde
Athanasios Anastasiou, Lecturer in Health Data Science, Swansea University Medical School, Swansea University
Amitava Banerjee, Senior Lecturer, University College London
Damon Berridge, Chair in Applied Statistics, Swansea University
Corri Black, Professor of Public Health, University of Aberdeen
Paul Burton, Professor of Data Science for Health, Newcastle University
Helen Colhoun, AXA Chair of Medical Informatics and Life Course Epidemiology, University of Edinburgh
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Richard Dobson, Professor of Clinical Epidemiology, University College London
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**e-infrastructure**

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Dr Philip Couch, Information Systems Programme Manager, University of Manchester
Professor David Ford, Deputy Centre Director, and Professor of Health Informatics, Swansea University
Simon Thompson, Chief Technology Officer, Swansea University
Dr Jacky Pallas, Director, UCL Research Platforms, University College London
Professor Mark Parsons, Director of EPCC and Associate Dean for e-Research, University of Edinburgh
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Professor James Cunnigham, Professor of Strategic Management at Newcastle Business School, Newcastle University

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Dr Nathan Lea, Senior Research Associate, University College London

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