Institution: University of Dundee
Unit of Assessment: UoA1 Clinical Medicine
Title of case study: Biomedical informatics transforming the care of people with chronic diseases internationally

1. Summary of the impact

A health informatics platform supporting chronic disease management nationally and internationally creating impact upon:

- **NHS:** Implementation in all 1043 general practices, 38 hospitals, and 14 Health Boards in Scotland, continuously monitoring care of 271,000 people with diabetes, with evidence of improved clinical outcomes.
- **Government Policy:** Embedded in Government policy: Scottish Diabetes Framework, Scottish Diabetes Action Plan; highlighted as "best practice" in the 2009 House of Lords Report *Genomic Medicine* and *UK Life Sciences Strategy* 2012.
- **Commercialisation:** A start up informatics company, now with 82 employees and deployments internationally.
- **Internationalisation:** Implementation of the informatics network through the Kuwait-Scotland eHealth innovation network.

2. Underpinning research

Diabetes is a global health problem. In December 1996 the United Nations declared diabetes to be a chronic, debilitating and costly disease associated with severe complications, which poses severe risks for the world. The number of people living with diabetes is estimated to be 500 million by 2030.

The underpinning research (1996-1998; Chief Scientist Office, Scottish Government-funded) was carried out at the University of Dundee and led by Professor Andrew **Morris** (Senior Lecturer in Medicine 1996-2000) with Professor Tom **McDonald**, Director of the Medicines Monitoring Unit who had pioneered record linkage for drug safety. The Diabetes Audit and Research in Tayside, Scotland (DARTS) study tested the hypothesis that record linkage of routinely collected NHS data sources was an efficient and accurate methodology to create a regional diabetes register. The initial study linked information from the community health index (health identity number), hospital clinics, pharmacies, laboratories, and the retinal screening service. The 1997 *BMJ* publication [i] reported on the sensitivity and specificity of this methodology for diabetes ascertainment and described the prevalence and morbidity of 7,500 people in Tayside Scotland (population 400,000). This initial success was followed by further underpinning research funding (Scottish Government 1999-2001) to demonstrate the scalability of the solution to another Health Board, initially NHS Forth Valley (population 350,000) in 2000. This developed and validated the informatics platform for the abstraction, normalisation, integration and provisioning of clinical data. It created a region wide clinical information system that provided value to frontline multi-disciplinary clinical teams across two Health Boards in Scotland. From 2002, the Scottish Government adopted the health informatics platform and implemented it across Scotland. It now supports care of 271,000 people with diabetes nationally and represents the most comprehensive clinical information system for the care of people with diabetes internationally.

From an academic perspective, the Dundee team not only built on the platform with >150 publications on classical epidemiology studies (Wellcome Trust/MRC funded [e.g. ii, iii]) but also anticipated the great value of combining routinely collected phenotypic data from electronic patient records with consented biologic materials, including DNA. This additional underpinning research was funded by local charities (£100K Tenovus Tayside; 1999-2002), and gained momentum with funding from the Wellcome Trust Functional Genomics Programme (£790K; 2003-2007) to create

the UK Case Control Collection for Type 2 Diabetes. This recruited over 20,000 subjects for genetic studies of diabetes, its complications and pharmacogenetics [e.g. iv]. This resource is the cornerstone of large international research collaborations including the Innovative Medicines Initiative and Wellcome Trust Case Control Consortium 2. The roll out to the whole of Scotland has allowed the study of the epidemiology, pharmacovigilance and outcomes research on a national basis, funded by the Wellcome Trust, MRC, ESRC as part of the £3.7M Scottish Health Informatics Programme (2008-2012) [e.g. v], and the recent 2012 award by MRC and nine other funders of a eHealth Informatics Research Centre; Dundee has been invited to lead the £39M UK network of eHealth Centres, *The Farr Institute for Health Informatics Research,* based upon this underpinning research.

3. References to the research (indicative maximum of six references)

i. **Morris** AD, Boyle DIR, MacAlpine R, Emslie-Smith A, Jung RT, Newton RW, **McDonald** TM (1997) The Diabetes Audit and Research in Tayside Scotland (DARTS) Study: electronic record linkage to create a diabetes register. DARTS/MEMO Collaboration. *Brit. Med. J.* **315**, 524-8 (DOI: 10.1136/bmj.315.7107.524).

ii. Schofield CS Yu N, Jain AS, Leese GP (2009) Decreasing Amputation rates in patients with diabetes – a population based study. *Diabetic Med.* **26**, 773-7 (DOI: 10.1111/j.1464-5491.2009.02770.x).

iii. Vallace JH, Wilson, PJ, Leese GP, McAlpine R, MacEwen, CJ, Ellis JD (2008) Diabetic retinopathy: more patients, less laser. *Diabetes Care* **31**, 1126-31 (DOI: 10.2337/dc07-1498).

iv. Zeggini E, Weedon MN, Lindgren CM, Frayling TM, Elliott KS, Lango H, Timpson NJ, Perry JR, Rayner NW, Freathy RM, Barrett JC, Shields B, Morris AP, Ellard S, Groves CJ, Harries LW, Marchini JL, Owen KR, Knight B, Cardon LR, Walker M, Hitman GA, **Morris** AD, Doney AS; Wellcome Trust Case Control Consortium (WTCCC), McCarthy MI, Hattersley AT (2007) Replication of genome-wide association signals in UK samples reveals risk loci for type 2 diabetes. *Science* **316**, 1336-41 (DOI:10.1126/science.1142364).

v. Colhoun HM and SDRN Epidemiology Group (2009) Use of insulin glargine and cancer incidence in Scotland: a study from the Scottish Diabetes Research Network Epidemiology Group. *Diabetologia* **52**, 1755-65 (DOI:10.1007/s00125-009-1453-1).

Funding

The research underpinning this case study has been funded by substantial research grants from a variety of peer-reviewed sources.

- **Morris** AD, Jung RT, **McDonald** TM: Does record linkage of drug consumption facilitate complete diabetes registration?; Scottish Home and Health Department (1996-1998) £105,752.
- **Morris** AD, Siann T, Jung RT, Newton RW, **McDonald** TM, Matthews D, Reith S: Innovative IT to implement the St Vincent Declaration and SIGN guidelines in Scotland; Scottish Office (1999-2001) £214,020.
- **Morris** AD¸ Davey PG, MacEwen CJ, Florey C du V: The epidemiology of diabetic eye disease: a population based study; Wellcome Trust (1998-2001) £177,104.
- **Morris** AD, Hattersley A, McCarthy M, Palmer C, Leese GP: The UK Type 2 Diabetes Genetics consortium Case-Control Collection: a resource for the genetic epidemiology of Type 2 diabetes; Wellcome Trust Functional Genomics Grant (2004-2006) £822,900.
- Multiple large International Grants including: Innovative Medicines Initiative (2010-2014, SUMMIT (complications of diabetes); €32M; joint PI Professor H Colhoun, University of Dundee leading on two work packages; 2012-2016 DIRECT Diabetes Research On Patient Stratification; €43M Professor Ewan Pearson Dundee, PI), Wellcome Trust Case Control Consortium 2; (Pharmacogenetics Exemplar; Professor C Palmer, PI).

4. Details of the impact

Government Policy Impact

Following publication of the underpinning research, Scottish Government endorsed the need for nationwide clinical information systems to support diabetes care through the Scottish Diabetes Group in the Scottish Diabetes Framework (2002) and the Scottish Diabetes Action Plans (2006 and 2010 [1]). The Government commissioned further informatics research at the University of Dundee to develop DARTS into a national technology product, the Scottish Care Information-Diabetes Collaboration (SCI-DC; http://www.sci-diabetes.scot.nhs.uk/) [2,3]. NHS Scotland Quality Improvement Scotland also endorsed its implementation for national clinical standards and retinopathy screening [4]. Every NHS Board in Scotland was instructed to deploy SCI-DC. The Government has funded SCI-DC as a joint venture between the University of Dundee and NHS Tayside (~£750K per annum during the assessment period), and it is now the national clinical information system for the care of all people with diabetes in Scotland. SCI-DC uses state-of-the-art informatics to combine information from heterogeneous data sources, including the national community health index, general practices, hospitals, laboratories and the national retinopathy screening service. Since 2004 SCI-DC has been implemented in all 14 Scottish Health Boards, and since 2008 it has been used in 1038 general practices and 38 hospitals, monitoring the care of over 271,000 people with diabetes. Since 2008 the SCI-DC has supported the nationwide retinopathy screening programme (http://www.ndrs.scot.nhs.uk/), arguably the most complete, quality assured screening programme internationally, performing digital retinal photography on 200,000 people with diabetes annually. SCI-DC also produces the Scottish Diabetes Survey [5] which has recorded year-on-year improvements in the quality of diabetes care, delivers national diabetes patient-led information and education packages (e.g. http://www.mydiabetesmyway.scot.nhs.uk/) and is embedded within national quality standards. In December 2008 SCI-DC commissioned an independent review of its products with a view to consolidating into a single system (SCI-DC Phase III) for diabetic care across Scotland, as well as moving to the latest relevant technologies, and in April 2013 the SCI-DC Team successfully completed the migration of Health Boards from SCI-DC Network to the single SCI-DC Phase III product now known as SCI-Diabetes [6].

Other impacts include:

- **Improved patient care and health outcomes:** SCI-DC supports the evaluation of improved regional and national health outcomes, e.g. a 40% reduction in amputation rates [ii] and a 40% reduction in sight-threatening retinopathy 2003-2009 [iii], and has evolved into a powerful nationwide pharmacovigilance tool, allowing safety assessment of diabetes treatments and other therapies [v].

1. **Strategic Research Impact:** SCI-DC is the core of the Scottish Diabetes Research Network (http://www.sdrn.org.uk/; Dundee led), that attracts research income (~£500K p.a.) from the Chief Scientist's Office to improve clinical trial performance (300% increase 2008-2013). The associated recruitment of individuals to large genomic studies (>40,000 subjects) [7,8], and the linkage of phenotype to genotype, has been of great importance [iv]. Dundee is now a major partner of several international research endeavours including the Wellcome Trust Case Control Consortium 2, the €43M DIRECT study on stratification of diabetes (led from Dundee) and the €32M SUMMIT study on biomarkers for diabetes complications (co-led by Dundee). Dundee leads the Scottish node of the £39M MRC co-ordinated Farr Institute and convenes the UK Health Informatics Research Network. In terms of research policy, this case study has been highlighted as best practice in the *UK Life Sciences Strategy* 2012, the UKTI "*Business Olympics*" at Lancaster House July 2012, and *The House of Lords Report on Genomic Medicine (2009)* [7]. The linkage between research, informatics and health care led Sir Mark Walport, Director of the Wellcome Trust to write (*The Times* 30th May, 2011); "If you live in Dundee and suffer from diabetes, you have recently been taking part in a medical revolution."

- **Creation of a new business:** In 2008 Aridhia Informatics (http://www.aridhia.com) was co-founded by the University with the aim of creating an international health informatics company

based in Scotland. Aridhia is now a small-medium enterprise, based in Dundee and Edinburgh, which employs 82 people. It has attracted >£10M of external investment, including a £1.2M Technology Strategy Board Cancer Informatics programme in Scotland, and venture funding from Scottish Equity Partners and Albion Ventures. Aridhia has cloud-based deployments in Scotland, England, Kuwait, New Zealand and Australia [9].

- **International Impact:** We have rolled out the informatics model internationally to the Kuwait-Scotland eHealth innovation network (www.dasmaninstitute.org/kuwait-scotland). The thesis is that we can export the Scottish Health Science "package" of informatics, research and quality care delivery to other nations wrestling with the challenge of non-communicable diseases. Following the signing of a Memorandum of Understanding in 2010 between the Ministry of Health in Kuwait, the Dasman Diabetes Institute [10], the University of Dundee, NHS Tayside and Aridhia Informatics, the partners have:
  - installed an electronic health record to the Capital Region of Kuwait City (600,000) with nationwide roll-out anticipated in 2013;
  - enrolled 170 Kuwaiti students on a University of Dundee Masters Course in Diabetes Care, Research and Education;
  - developed the Kuwait clinical skills centre, the first of its kind in the Middle East;
  - established collaborative research programmes in genetics, epidemiology and health services research;
  - secured multi-million pound income to Scotland (>£15M);
  - been shortlisted for the *Times Higher Education Supplement* International Collaboration of the year 2012.

5. Sources to corroborate the impact

Evidence of **impact into everyday clinical care** across Scotland, and **commercialisation** can be confirmed from the following websites and individual contacts:

1. The Scottish Government, Edinburgh (2010) Diabetes Action Plan 2010: Quality Care for Diabetes in Scotland. ISBN: 978-0-7559-9379-6; available at: http://www.diabetesinscotland.org.uk/Publications/DAP2010.pdf.
2. Corroboration of statements regarding the roll-out of the SCI-DC across Scotland may be obtained from the former Lead Clinician for Diabetes in Scotland.
3. Corroboration is also available from the Chair of the SCI-DC Steering Group.
4. NHS Quality Improvement Scotland (2008) National Overview Follow-up Report ~ March 2008: Diabetes. ISBN 1-84404-499-8; available at: http://www.healthcareimprovementscotland.org/previous_resources/performance_review/diabetes_follow-up_no.aspx.
5. NHS Scotland Scottish Diabetes Survey Monitoring Group (2009) Scottish Diabetes Survey 2008: http://www.diabetesinscotland.org.uk/Publications/Scottish%20Diabetes%20Survey%202008.pdf
6. http://www.sci-diabetes.scot.nhs.uk/history-2/
7. House of Lords Science and Technology Committee; 2nd Report of Session 2008–09 Genomic Medicine Volume I: Report. Available at: http://www.publications.parliament.uk/pa/ld200809/ldselect/ldsctech/107/107i.pdf
8. Further corroboration may be obtained from the Chair of the Office of Strategic Co-ordination of Health Research (OSCHR).
9. Corroboration may be obtained from the Chief Executive Officer of Aridhia Informatics.
10. Corroboration may be obtained from the Director, Dasman Diabetes Institute Kuwait.