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Maximising the Use of Routine Data for Research in Wales

The National Institute for Social Care and Health Research (NISCHR)



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Vision

NISCHR's mission is to support today's research to inform tomorrow's care. The vision is to make Wales a first-class environment for health and social care research, building on excellence and fostering activity that can inform and drive improvements to health and well-being in Wales.

This document outlines NISCHR's plans to broaden our investment in approaches to utilise routine data for research – approaches that can offer new ways to investigate and understand factors affecting health and illness in the population, and how research using routine data can translate into direct benefits for people in Wales.

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1. The Strategic Context

- 1.1 NISCHR is the Welsh Government body that develops, in consultation with partners, policy on research and development to reflect the health and social care priorities of the Welsh Government. NISCHR delivers its strategy and policies through commissioning services, running research schemes and initiatives, and through strategic investment and partnership working with other funding bodies and industry.
- 1.2 NISCHR policy and activity is closely aligned with the broader strategic agendas for health, social care and science in Wales, articulated in key Welsh Government publications.
- 1.3 Together for Health¹ sets out the vision for the NHS in Wales and describes a focus on delivery and making significant improvements over the next five years. Many improvements in care come about through the timely adoption of the findings of research and the evaluation of current practice and research and innovation activities will have a major contribution to make here.
- 1.4 Sustainable Social Services for Wales: A Framework for Action² recognises the need for social services to evolve and adapt to a changing Welsh demography. There is acknowledgement that, in future, social services will need a much greater focus on evidence-based practice. NISCHR initiatives aim to strengthen the quality and quantity of social care research and to develop research collaborations between practice and the research community.
- 1.5 *Science for Wales*³ provides a vision for a strong and dynamic science base, essential for the economic welfare and national development of Wales and recognises life sciences and health as one of three grand challenge areas. The strategy calls for an “innovative, evidence-based health and social care system for Wales underpinned by the use of nationwide integrated health and social care data, and on an excellent life sciences and health research foundation.”
- 1.6 In line with these publications, NISCHR has developed *Together for research and innovation 2012-2015*, a strategy which outlines our primary goals to support research and innovation in health and social care to raise the level of health and well-being of people in Wales and contribute both directly and indirectly to wealth generation.
- 1.7 Drawing on the intention to make smarter use of data as outlined in *Together for research and innovation*, this document provides greater detail on NISCHR’s objective to build on the existing research strengths in Wales and promote a culture where the smarter use of routine data can both enhance and offer new opportunities for research.

¹ *Together for Health (2011) A Five Year Vision for the NHS in Wales. WG 14021 ISBN 978 0 7504 6808 4*

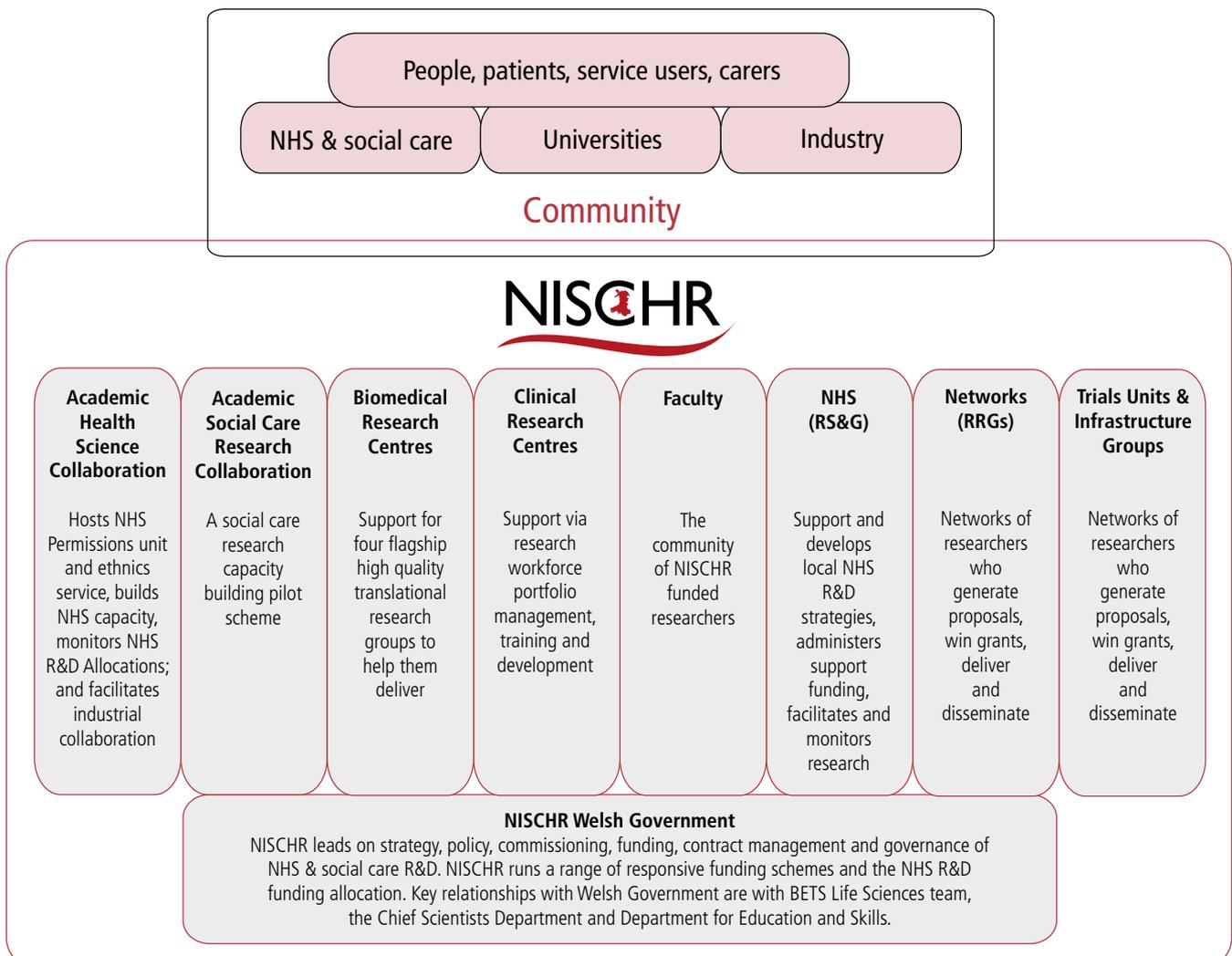
² *Sustainable Social Services for Wales (2011): A Framework for Action. Number: WAG10-11086*

³ *Science for Wales (2012) A strategic agenda for science and innovation in Wales. ISBN 978 0 7504 7150 3 / WG 14478 GIMHI4247*

2. The NISCHR Research Infrastructure

- 2.1 The NISCHR commissioned infrastructure supports excellence and builds capacity in health and social care research across Wales. The funded components of the NISCHR infrastructure undertake and support a wide range of activity across the NHS, social care and academic sectors. Figure 1 below shows the complete NISCHR infrastructure.
- 2.2 Increasing support for the use of routine data for research will be relevant to many of the infrastructure components, particularly the Academic Health Sciences Collaboration and All Wales Academic Social Care Research Collaboration who can support and facilitate the use of routine data, and the Biomedical Research Centres, Units and Registered Research Groups who can make use of greater access to data to enhance their research as well as offering datasets for further linkage.
- 2.3 The support and engagement of the NISCHR infrastructure will be essential if we are to be successful in embedding a culture of research in Wales that fully utilises the routine data resources available.

Figure 1: the Health and Social Care Research and Innovation Structure and Functions of NISCHR



3. The Smarter Use of Routine Data for Research

- 3.1 The level of national and international recognition of the importance of the smarter use of routine data, and its value to research, has never been greater. The key role of routine data in the future of health and social care research is reflected in a number of strategic publications by UK Government, Research Councils and Charities.⁴ The £19 million investment in e-health research Centres of Excellence by a consortium of ten UK government and charity funders⁵, along with the recently published recommendations of the Administrative Data Task Force (ADT)⁶ gives a strong and clear impetus for increasing efforts to capitalise on the opportunities that research using routine data can offer.
- 3.2 NISCHR believe that the current strengths in Wales provide a unique environment where research using routine data can flourish. Wales now boasts internationally recognised expertise in data linkage, a well-established health-informatics platform and a highly-skilled research community who understand the promise of routine data and are eager to draw upon it for research.
- 3.3 These research strengths are supported by a devolved health service in Wales where responsibility for primary and secondary care is integrated within single health boards. The central management of national NHS IT programmes through NHS Wales Informatics Service (NWIS) provides a simple interface for communication and collaboration on NHS data issues, and NWIS are active supporters and partners in efforts to maximise the value of routine data for secondary uses such as research.
- 3.4 NISCHR will build on our research excellence, invest in new approaches to capitalise on our rich history of public and community engagement in research, and look to support activities for the future where genetics and genomics can have a key role in healthcare provision. We intend to promote a culture where the smarter use of routine data can both enhance and offer new opportunities for research, and help to optimize the care and services we provide.
- 3.5 Health policy articulated in Together for Health places an emphasis on preventative, patient-centric and sustainable healthcare in order to tackle the challenges that face NHS Wales. Furthermore, *Sustainable Social Services: A Framework for Action* proposes high quality, citizen-centred social services that are responsive to our changing society. NISCHR's support for research utilising routine data reflects the contribution we believe it can make to help address the key questions and issues to overcome the current challenges facing the NHS and social services in Wales.

⁴ These Strategic Publications include: *The Age of Bioscience Strategic Plan 2010–2015*, Biotechnology and Biological Sciences Research Council (BBSRC); *Strategic Plan – Research Changes Lives – 2009–2014*, Medical Research Council; *Strategic Plan 2009–2014*, Economic and Social Research Council; and *Strategic Plan 2008–2013*, National Cancer Research Institute; *Strategic Plan for UK Life Sciences*, UK Government 2011

⁵ Further information on the E-Health Research Initiative and the funders involved can be found at: <http://www.mrc.ac.uk/Newspublications/News/MRC008799>

⁶ The UK Administrative Data Research Network: Improving Access for Research and Policy, December 2012. <http://www.esrc.ac.uk/funding-and-guidance/collaboration/collaborative-initiatives/Administrative-Data-Taskforce.aspx>

- 3.6 Effective reconfiguration of healthcare services, alongside the development of integrated health and social service provision are key policy priorities for Welsh Government, and it is vital that the changes and improvements to care and services are evidence based. Research using routine data can allow us to evaluate existing healthcare provision and services, and propose new interventions, at an individual, community and population level. Smarter use of routine data can empower decision-makers to optimize the services provided by local health boards and local authorities. Data linkage can offer new ways and means for research to investigate the underlying socio-economic factors that impact on the health and well-being of the people in Wales.

NHS Wales Informatics Service (NWIS); Supporting Health Records Research

NWIS has a vital role in enabling and supporting the availability of routine data for research purposes. NWIS is responsible for the roll-out of common systems for pathology, radiology and medicines services in Wales, as well as the management of a number of national datasets, including Cancer Registry Information, Patient Episodes Data and Screening Services Data. These systems and datasets capture routine data that can be valuable to support health records research.

NWIS plays a key role in the anonymisation processes, working in collaboration with the Health Information Research Unit to make routine data available for linkage and research use in a way that ensures the appropriate confidentiality and security is maintained. NWIS provides a Trusted Third Party service in handling the identifiable components of datasets to be included in SAIL. They carry out the matching process, anonymise the data and allocate a unique anonymous linking field (ALF) to each record so that the records can be reliably linked whilst ensuring data protection.

NWIS colleagues are directly involved in the Information Governance Review Panel (IGRP) that assesses research applications proposing to use SAIL to access linked, anonymised routine data.

- 3.7 These activities must balance the public benefit of access to routine data to support research, with the rights for privacy and patient confidentiality. Fostering public confidence and trust, and empowering patients to have greater involvement in research that can directly affect the care and interventions they receive, will be central to approaches supported by NISCHR for the more effective use of routine data for research.
- 3.8 The establishment of NWIS Welsh Information Governance Board and its Privacy Advisory Committee will provide a national framework to refine, endorse and support approaches to facilitate the safe, secure, ethical and efficient use of data for research. Alongside these governance developments, the increasing value of patient-reported outcomes, and web-based portals to facilitate interaction with patients, can offer new ways to engage with patients, seek consent, conduct research and link data for further research utility.

- 3.9 Public engagement and trust are paramount to efforts for making better use of routine data for research. The report from the Administrative Data Taskforce includes a recommendation for the development of public engagement strategies around access to administrative data for research purposes, and the new Caldicott Review⁷, exploring the balance between protecting patient information and its sharing to improve patient care, is due to report in Spring 2013. This work will be vital to informing the future development of appropriate models of public and patient engagement for routine data research in Wales.
- 3.10 At a time when cost and lengthy start-up factors are undermining the UK's ability to remain a competitive destination for clinical trials, we must also look to capitalise on our assets and strengths to attract investment for health and social care research in Wales.
- 3.11 NISCHR recognises opportunities in the way that more effective use of routine data can appeal to industry partners, particularly where we can offer faster and better recruitment of stratified patient groups to trials, and greater access to real world data for health economic analysis. Significant developments here will allow us to demonstrate the vital contribution that research can make, not only to health, but also to the wealth and economic renewal agenda in Wales.
- 3.12 This document focuses on four key themes where we have significant opportunities to capitalise on strengths in Wales:
- **Building on excellence** by capitalising on our expertise in data linkage, encouraging use and enhancing access to these resources for research;
 - **Building on a legacy** by utilising technical developments and Welsh researcher experience to develop large numbers of prospectively-consented patients to be involved in research;
 - **Building for the future** by addressing capacity issues in bioinformatics to support research in Wales to ensure that we are able to capitalise on advancements in linking routine data with genetic and genomic data; and
 - **Supporting effective healthcare delivery** by encouraging Welsh NHS organisations to take opportunities to use data to improve service provision through operational research, simulation and modelling.
- 3.13 NISCHR also recognises the broader potential use of routine data activities beyond that for health and social care research purposes. Maximising the use of routine data can play a key role in enhancing the evidence base and offering innovative approaches to policy development and evaluation. The Welsh Government, along with the Economic and Social Research Council (ESRC), has jointly funded four research fellowships to explore the best ways forward in terms of delivering more broadly based socio-economic data linking capacity for Wales. Recommendations in the Administrative Data Taskforce report for the creation of four Administrative Research Data Centres across the UK will only increase the drive to build on Welsh capabilities in this area and opportunities are equally promising for data linkage strengths to serve the commercialisation agenda.
- 3.14 It will be vital that a coordinated approach is taken to balance the priorities, find solutions to common barriers and ensure that delivery is achieved for all potential uses. Complementary to the activities proposed in this vision document, NISCHR will work with other Welsh Government colleagues to develop a common approach to maximise the value that data can offer.

⁷ Caldicott 2: Information Governance Review Report. Expected publication in April 2013 <http://caldicott2.dh.gov.uk/>

4. Building on Excellence

- 4.1 Over the past 6 years, NISCHR has funded the Health Information Research Unit (HIRU)⁸ in the development of expertise in health informatics and the creation of the Secure Anonymised Information Linkage (SAIL) databank to offer a platform to explore the potential of linked, anonymised, routinely-collected electronic data for research.
- 4.2 The achievements of HIRU to date in demonstrating the ability to make use of routine data for research has been recognised with the success of a HIRU-led collaboration being established as one of four UK E-Health Research Centres of Excellence.
- 4.3 The Centre for Improving Population Health through E-Health Research (CIPHER) will undertake a high-quality programme of research as well as deliver on training and capacity building objectives to develop a cadre of highly-skilled health informatics professionals. CIPHER will combine with the other successful research teams to form a UK network of e-health centres, with unique opportunities to influence and shape the future landscape of e-health research.
- 4.4 With this recognised badge of excellence for Welsh researchers, NISCHR is keen to ensure that we can maintain our place at the forefront of data linkage developments and maximise the ways in which it can support the health and social care research environment. There is a drive at UK level to open up greater access to data and as these initiatives begin in earnest, we must ensure that the research infrastructure and community in Wales is ready to reap the benefits.

The Wales Electronic Cohort for Children (WECC)

The Wales Electronic Cohort for Children (WECC) is one of SAIL's flagship studies. WECC is a total population anonymised e-cohort study of children (n=804,209) who were born or lived in Wales between 1990 and 2008, created from multiple datasets. It represents a major research collaboration between Swansea and Cardiff Universities. There are four research themes exploring the health consequences of different exposures: babies born preterm or small for gestational age; environmental influences on obesity; frequent house moves; and the inter-relationship between health and education. The sheer scale of WECC means that it can provide answers to difficult to research questions, such as the impact of each week of prematurity on respiratory health, or the impact of breast feeding or garden size on childhood obesity at school entry. WECC was initially designed as a proof of concept study but results are already being used by Welsh Government in policy appraisal and development.

The second phase of WECC will concentrate on the inter-relationship between health and education and using the platform to evaluate a number of natural experiments, trials and policy interventions, with the support of the two UK research centres of excellence based in Wales: CIPHER and DECIPHer.

- 4.5 The SAIL databank, and the methodological and technical expertise possessed by HIRU, offers an exceptional asset for research in Wales. The value of this asset is borne out by the capture of more than £41million in grant funding for projects led or contributed to by HIRU to date. To further expand the impact of SAIL and data linkage for research purposes, we must continue to support efforts to increase access to routine data and other data available for linkage, and improve the availability of the analytical capacity and capabilities that can generate high quality research from it.

⁸ <http://www.swansea.ac.uk/medicine/ils/healthinformationresearchunit/>

- 4.6 The more comprehensive the data, and the greater its quality, the more valuable SAIL will become in supporting research. SAIL already contains over 2.5 billion rows of linkable data, with information from a wide array of health and non-health datasets, including national screening programmes, prescribing data, pathology data, and several others on a national scale.
- 4.7 **NISCHR will work alongside HIRU with key partners in Welsh Government and the NHS Wales Informatics Service (NWIS) to address access to NHS and administrative datasets, and explore opportunities to improve the quality of routine data. We will also work with HIRU to speed up the processes to make the anonymised data available for research.**
- 4.8 Some of these activities are already underway. Through investment in the NISCHR Academic Health Science Collaboration (AHSC)⁹, funding has been provided to support a focused piece of activity to enhance the ability of SAIL to capture and provide comprehensive and accurate NHS clinical data for research. This complements a further drive from NISCHR to facilitate an initiative, alongside GP and research champions, to promote general practice engagement with SAIL and increasing GP practice sign-up to provide routine data.
- 4.9 Activities to capitalise on routine data and data linkage are not limited to Wales and the development of data linkage capability throughout the UK provides opportunities for researchers to use datasets from more than one nation. NISCHR will ensure that we work effectively with other UK developments, particularly the Clinical Practice Research Datalink (CPRD)¹⁰ in England and the Scottish Health Informatics Programme (SHIP)¹¹ in Scotland, to share good practice and enable appropriate linkage with SAIL.
- 4.10 The breadth of data held securely in the SAIL databank includes information from both health and non-health datasets. The ability to link health and non-health related data offers a unique resource for research to explore the economic, environmental and social determinants of health and well-being, with huge value for both NHS and social services. Whilst much of the current activity is NHS focused, **NISCHR is committed to working with stakeholders, including Welsh Government departments, local government organisations and the Wales Institute of Social and Economic Research, Data and Methods (WISERD)¹², to scope the needs of the social care community for data linkage support for research and potential models to develop capacity.**
- 4.11 We have been successful in establishing the use of routine data and data linkage as a core part of the Welsh research environment, but we can still do more to improve the 'researcher experience' of using SAIL as a platform for research by adding more data, obtained in a timely way, and by streamlining the processes by which a researcher may gain access. The creation of the SAIL Gateway enables remote analysis of data held within a secure setting and its strengths in providing such facilities has meant that the Gateway is increasing being used to provide safe access to other UK datasets. **NISCHR has requested that HIRU review the current processes for researcher access to SAIL, to achieve a balance between information governance and the timely approval of proposed uses of SAIL data for research.**

⁹ <http://www.wales.nhs.uk/sites3/page.cfm?orgid=952&pid=51981>

¹⁰ <http://www.cprd.com>

¹¹ <http://www.scot-ship.ac.uk/>

¹² <http://www.wiserd.ac.uk/>

4.12 Making the 'researcher experience' as simple and straightforward as possible is vital if data linkage is to be fully embraced by the research community. It is this community that can drive the research outputs, using the SAIL platform to complement and enhance research activity. NISCHR has funded posts in four Registered Research Groups (NISCHR RRGs), working exclusively with HIRU to demonstrate how data linkage of electronic health records can support and enhance their research portfolios. **These posts will run until 2013 and we will review the effectiveness of the experience and outputs they achieve. NISCHR will also review this model of working and consider how best this approach can be sustained and expanded.**

5. Building on a Legacy

- 5.1 Advances in computational power and web technology have opened up possibilities for large-scale data collection and analysis that has previously been prohibitively expensive and difficult to manage through more traditional methods.
- 5.2 The legacy of successful Valleys epidemiology studies developed by Archie Cochrane, and a whole practice population approach to research and care pioneered by Julian Tudor-Hart sets a precedent for the impact and benefits for healthcare that can be achieved through large scale, in-depth population studies.
- 5.3 NISCHR is keen to promote and support efforts to establish an e-cohort large population study, exploiting web-based cohort and data linkage expertise to create a real world 'laboratory' in Wales for research to investigate social, economic, environmental and healthcare determinants of health and well-being.
- 5.4 The development of prospectively-consented e-cohorts based on routine data, to complement existing e-cohorts utilising anonymised data, can allow research and evaluation to take place close to the patient/doctor interface, offering an innovative approach to the generation of evidence and timely implementation of interventions to address some of the most difficult challenges facing the NHS in Wales – tackling the continuing inequalities in care, and providing effective and sustainable services by targeting the most effective services to be delivered in the community.
- 5.5 As with the whole population approaches to research of our past, establishing a culture of engagement on a large scale, where patients are well-informed and proud to be part of studies and activities that can impact not only on the care and services they receive, but also in contribution to broader questions about population health, makes for an exceptional asset for research.
- 5.6 Large population studies create a framework to conduct trials and evaluations of health systems, services, public health and healthy lifestyle programmes. This platform can provide opportunities for a wide range of stakeholders, including NHS clinicians and managers, policy makers, academics and industry, to test research questions, as well as establishing a rich dataset that can be embedded within SAIL to further increase its value.
- 5.7 Drawing together the skills and expertise of Wales School of Primary Care Research¹³, the record linkage facilities of SAIL and the experience of creating web-based cohorts as part of UK Biobank¹⁴, we have all the requisite elements to be successful.
- 5.8 Web-based technology has allowed the creation of portals for direct patient contact, directly engaging with populations outside of the traditional healthcare settings. These tools offer facilities to undertake research in new ways, capturing patient reported outcomes data that can complement routinely collected data from administrative systems. Pilot work undertaken between Swansea University and Quintiles has demonstrated the feasibility of linking SAIL data with patient reported outcome data, and NISCHR is keen to work in partnership to expand these activities.

¹³ <http://www.cardiff.ac.uk/wspcr/index.html>

¹⁴ <http://www.ukbiobank.ac.uk/>

Wales SAIL and Patient Reported Outcomes (WASPS) Study¹

In late 2011, Swansea University, custodians of the SAIL databank, undertook research with Quintiles to ascertain the possibility of recruiting patients for an observational study involving linkage of Patient Reported Outcomes (PRO) collected by Quintiles Digital Patient Platform, with the Electronic Health Record (EHR) held within the SAIL databank.

Interested individuals clicked a link to access study information and screen based on self-reported data and willingness to have data linked to the SAIL databank. 95% of all responders were comfortable linking their PRO, obtained by Quintiles, to their EHR in SAIL, demonstrating an appetite from the people of Wales to take part in such a ground breaking study which has not yet been conducted elsewhere in the UK. In total, 98 Welsh members of MediGuard.org, one of Quintiles patient communities², and 142 individuals recruited through other online channels enrolled into the study.

Not only did this research collaboration between Swansea University and Quintiles demonstrate that PRO + EHR linkage can be delivered, but it also provided some interesting healthcare insights. For example, in this study group, 95% of patients with high cholesterol are prescribed a statin, with 73% being prescribed simvastatin, a cost effective approach to treatment. And yet, 91% of patient expressed somewhat, little or no knowledge about their treatment, with only 40% demonstrating medication adherence based on a MARS-5 score. Such patient insight begins to identify the need for patient support programmes, in order to maximise adherence. Without such programmes in place the patients, and society, will not be getting the desired health and economic outcome benefits, which are so important.

This collaboration between Swansea University and Quintiles, a major player in the healthcare industry, demonstrates a new and cost efficient method of patient engagement for research purposes across clinical studies in terms of feasibility, recruitment and retention. It enables "Real World Data" collection, which is very important in today's Quality of Life and Valued Based Prescribing environment. Finally, it also helps to highlight the need to identify and address medication adherence. All these approaches are of value to the healthcare industry and thus make Wales a very attractive proposition for inward research investment.

¹ Cascade E, Nixon M, Ford D, Brooks C, Heaven M: Combining Electronic Health Records and Patient-Reported Information in the UK: Preliminary Results from the WASPS (Wales SAIL + PRO Study). ISPOR June 2012.

² Quintiles online communities (MediGuard.org, ClinicalResearch.com, Facebook - lammorethanlupus): 3.0 million globally.

- 5.9 NISCHR investment through AHSC is already providing funding to further develop web-based technologies that allow patients and the public to join e-cohorts and to facilitate the remote conduct of epidemiological studies.
- 5.10 NISCHR will promote collaboration between academic, industry and NHS partners to bring together research excellence and expertise to achieve this venture. We will explore funding opportunities to establish pilot studies.

6. Building for the Future

- 6.1 Wales is one of a small group of countries that can demonstrate real success in realising the potential of electronic health records for research. We have exploited our small scale to enable close collaboration between researchers that has allowed all-Wales enterprises to develop and thrive. These achievements could soon be overshadowed by the sheer volume of data available in other UK countries once equivalent health informatics infrastructures are up and running. It will be important to ensure that Wales continues to play a role in this vibrant R&D endeavour, but to remain at the forefront of developments, we need to capitalise on opportunities to broaden the appeal of Wales as a venue for high quality research using routine data.
- 6.2 It has been recognised that capability to link routine data with genomic data is currently under-developed in the UK, and could have a huge impact on the amount of research possible and play a key role in the integration of stratified medicine in healthcare.
- 6.3 The House of Lords Science and Technology Committee has highlighted that addressing the challenges of handling the linkage of medical and genetic information would maximise the value of these unique sources of information.¹⁵ Furthermore, the advent of advanced, low cost molecular and genetic techniques, together with more detailed and ubiquitous electronic patient record platforms, can enable a convergence of skills and data technologies that can be combined and exploited for research gain.
- 6.4 In line with this, NISCHR is looking to facilitate and support efforts to explore the feasibility of linking routine data with genetic and genomic data, creating a new dimension to the way in which data linkage can deliver new research possibilities.
- 6.5 Making these linkages will have benefits for both patients directly, by improving patient care and decision making, and indirectly by enabling research for the public good to unravel the role of genetic, environmental and lifestyle factors in disease.¹⁶
- 6.6 In preparing for this future, we are working from an established base. Alongside our data linkage excellence, Wales is home to a highly respected genetics and genomics research community and has involvement with a number of UK initiatives.
- 6.7 The National Centre for Mental Health Biomedical Research Centre¹⁷, the Wales Gene Park, the Wales Cancer Bank and the Cancer Genetics Biomedical Research Unit¹⁸ are flagship programmes funded by NISCHR that recognise and support research excellence in genetics and genomics.
- 6.8 Wales is participating in UK Biobank, looking at the combined effect of genetics and lifestyles on disease and the Biobank Participant Resource Centre, hosted by Cardiff University, has recruited 50,000 Participants to the study. The Cardiff Experimental Cancer Medicine Centre and the All Wales Medical Genetics Service have been recognised respectively as clinical and technical hubs as part of phase 1 of Cancer Research UK (CRUK) stratified medicine

¹⁵ House of Lords Science and Technology Committee (2009) *Genomic Medicine – Volume 1: Report 2nd Report of Session 2008–09*

¹⁶ House of Lords Science and Technology Committee (2009) *Genomic Medicine – Volume 1: Report 2nd Report of Session 2008–09*

¹⁷ <http://ncmh.info/>

¹⁸ <http://medicine.cf.ac.uk/cancer-genetics/cancer-genetics-biomedical-research-unit/>

programme.¹⁹ The programme will analyse a prioritised set of genes and mutations associated with a variety of tumours, and combine this with routine clinical data to form cohort datasets of mutations, treatments and outcomes. This marks a significant step in making targeted therapies available for people with cancer in the UK and can play a key role in the integration of stratified medicine in healthcare.

- 6.9 These programmes of research provide a focus for us to build on. To be successful, we must ensure that collaboration between our centres of excellence can flourish and that we have sufficient capacity to overcome the challenges and pursue the feasibility of linking routine data with genetic and genomic data for research gain.

The PsyCymru Study

PsyCymru is a NISCHR funded study to establish the feasibility of creating a psychosis cohort in Wales. An electronic cohort of all people with psychosis in Wales is being created using the anonymised, routinely collected electronic health records housed in SAIL databank. This e-cohort will be linked to a prospectively ascertained, fully consented live cohort of people with psychosis, who will receive in depth clinical interviews and genetic testing.

The purpose is to learn more about the interactions between biological, psychological and social risk factors leading to onset and relapse. The efficacy of current treatment interventions will also be evaluated. A better understanding of the causes, course and outcomes of psychosis can contribute to the development of better diagnostic, predictive, preventative and therapeutic approaches. Recruitment to this study closed in March 2012 and the study data is currently being cleansed and loaded into SAIL to create a research-ready platform for analysis. This highly characterised cohort (clinical and genetic data) can be linked to the retrospective data within multiple datasets from primary and secondary care in SAIL, allowing specific research questions to be addressed.

- 6.10 The recent Human Genomics Strategy Group report, *Building on Our Inheritance*²⁰, outlines the barriers that must be overcome and highlights the essential role that bioinformatics will play for the NHS to capitalise on benefits that genomic technologies can bring. The development of an appropriate ethical framework, as well as having the necessary infrastructure in the NHS to receive and utilise genomic technology, both in terms of technical and human capacity, present challenges to the adoption of these technologies.
- 6.11 These issues are actively being tackled at a UK level and we must engage with this agenda to ensure that we too can contribute to this emerging area and reap the benefits for healthcare in Wales. There is a shared enthusiasm across Welsh Government departments that Wales should be ambitious in its plans to use genomic data for clinical, research and economic benefit. NISCHR is supportive of the desire to expand the infrastructure for capture, storage and analysis of genetic and genomic data in Wales, and we will be working to ensure that there is a close and harmonised relationship between its value for clinical services and for research.

¹⁹ <http://science.cancerresearchuk.org/research/how-we-deliver-our-research/others/by-programme/stratified-medicine-programme/>

²⁰ *Building on our Inheritance, Genomic Technology in Healthcare*; A Report by the Human Genomics Strategy Group, January 2012

- 6.12 There is an opportunity to invest in our existing research infrastructure that can make a significant contribution to our long term aims. To support this, **NISCHR will look to develop specific funding calls to address bioinformatics capacity in Wales and consider the future alignment of funding to meet this strategic agenda.**
- 6.13 The forthcoming NISCHR experimental medicine research strategy (2013) will include a focus on efforts to consolidate human tissue resources in Wales. We will be working to ensure that the power of these resources can be enhanced with opportunities to enable linkage with routine data. NISCHR has provided funding through the NISCHR AHSC Biobanking Research Support Scheme, offering resource for a small number of posts to undertake linkage between tissue collections and clinical data, providing a foundation for work in the future. Barriers that limit access to identifiable routine clinical data have hampered efforts to match genetic information to clinical records even though patient consent is present for such activity. Finding appropriate ways to unlock routine clinical data for patient-identifiable research is important to enable this type of research to contribute to improvements in treatment and patient care. **NISCHR will work with colleagues in the clinical research infrastructure and Local Health Boards to find adequate solutions to this issue.**

7. Supporting Effective Healthcare Delivery

- 7.1 *Together for Health* puts a clear focus on delivery of world-class health and social care for Wales and the ability to offer sustainable and reliable services. Research and evaluation is essential to provide an evidence base that can inform the development of more efficient and effective delivery of healthcare services in NHS Wales.
- 7.2 Greater collaboration between Welsh academia and NHS Wales that harnesses the power of increased availability and access to routine data can enable new research focussing on service delivery and organisation issues.
- 7.3 The strengths being combined through the Health Modelling Centre Cymru (HMC²)²¹ is a good example of how an all-Wales initiative that focuses on promoting interaction between mathematical and computational modelling and health delivery can show benefits. The development of partnerships between such academic ventures and NHS Wales can transform the quality and cost of healthcare delivery through simulation and modelling.
- 7.4 Techniques such as mathematical modelling can help analyse complex scenarios and gives those responsible for the delivery of NHS services better tools to make more effective decisions.

Using Operational Research to Optimize Service Delivery

An Emergency Unit (EU) is a vital component within a health system, and yet EUs frequently struggle to meet demand. A common operational response to these events is to increase trolley capacity within the unit. As a consequence greater expenditure is incurred resulting in an increase in average unit costs and, in many circumstances, only a transient improvement in performance is realised. In response to this problem Cardiff and Vale Health Board collaborated with the Health Modelling Centre Cymru to redesign patient flows and determine optimal resourcing levels.

Methodologies drawn from the discipline of Operational Research (OR), such as queueing theory and computer simulation, are able to create 'real world' models of the EU and permit 'what if?' scenarios to evaluate the impact of changes to the system. The approach taken at the University Hospital of Wales was novel in that a 'perfect world model' was built. The EU was modelled not as it is, but as it could be. The 'efficiency gap' between the 'perfect world' and the 'real world' identified the location of bottlenecks in the current 'whole hospital' patient pathway.

In particular it was identified that the number of trolleys in the EU could be reduced by 43% which would permit reallocation of capacity so as to reduce bottlenecks. It was estimated that such a reduction of number of trolleys corresponds to a saving of about £2.5m per year. This is a level of resource that could be invested in the additional Clinical decision makers identified as being required to meet demand. We identified that there is the potential to realise net efficiency gains of about £1.6m per year in the EU. As of Summer 2012, based on implementing the recommendations of the study, the Health Board has managed to-date to reduce trolley capacity by 20% and reduce nursing staff in the department by commensurate levels, and has gone out to advertise for a further four consultant A&E doctors. This is part of an on-going rolling implementation plan with further future benefits anticipated.

Kesh Baboolal, Jeff Griffiths, Vincent Knight, Andrew Nelson, Cheryl Voake, Janet Williams (2012) "How efficient can an emergency unit be? A perfect world model". *Emergency Medicine Journal* (EMJ Online First, published on February 14, 2012 as 10.1136/emmermed-2011-200101)

²¹ <http://hmc2.cf.ac.uk/>

- 7.5 A number of Health Boards in Wales have already begun to engage with this agenda and Aneurin Bevan Health Board has recently undertaken a new partnership with HMC², jointly funding 4 posts that will develop research programmes based on real world data generated by the health board. The research and evaluation generated will be able to inform decisions around service configuration and delivery. NISCHR encourages this cohesive approach between academic strengths in operational research and modelling and Health Boards in NHS Wales.
- 7.6 The access and data linkage facilities provided by SAIL can enable simulation and modelling to have broader appeal to NHS Wales. For example, linkage of individual health records and PAS data can open up possibilities for dynamic health services scheduling that can optimise services to meet demand and make most effective use of resources.
- 7.7 The Health Information Research Laboratories, a partnership between Swansea University and NWIS focuses on evaluation research and innovation that supports real patient benefits to the NHS in Wales and beyond through the delivery of healthcare IT innovations, centred on the patient. The facility can draw upon the combined expertise of university researchers, NHS staff (clinical, managerial and IT), and NWIS domain experts to undertake robust, impartial and pragmatic assessments of technology to support healthcare delivery.
- 7.8 NISCHR will explore the support required to develop capacity for operational research and modelling, and facilitate collaboration between Health Boards and our academic strengths.

8. Next Steps

- 8.1 This policy outlines a broad vision to facilitate and support delivery of new and enhanced approaches to maximise the use of routine data for research. This must be a combined endeavour, and NISCHR support and funding needs to be targeted strategically to complement the range of activities, both planned and underway, in the R&D community. It is of great importance that the research infrastructure, and R&D community as a whole, is engaged, where necessary, to foster an environment where real success can be achieved.
- 8.2 There are a number of organisations in Wales that will have an interest and a stake in the success of these approaches, and collaboration is vital if we are to fully realise the benefits. To facilitate progress against this vision, NISCHR will establish a steering group, with an independent chair, to coordinate and prioritise activities, and to ensure that effective partnerships can be pursued and maintained to effectively address common issues and collaborate to maximise the potential for delivery.
- 8.3 The policy proposes that NISCHR will:
- work with key partners in Welsh Government, NWIS and HIRU to address access to NHS and administrative datasets
 - work with HIRU to speed up the processes to make 'clean' anonymised data available for research, to enhance the 'researcher experience' by reviewing the current processes for researcher access to SAIL, and to establish a balance between information governance and timely approval of proposed uses of SAIL data for research
 - work with NWIS National Information Governance Board to continue to develop approaches that can facilitate safe, secure, ethical and efficient use of data for research
 - scope the needs of the social care community for data linkage support for research and potential models to develop capacity
 - review the progress achieved by the four NISCHR RRG informatics posts and consider how best this approach can be sustained and expanded
 - explore funding opportunities to establish pilot studies for prospectively consented large population e-cohorts
 - look to develop specific funding calls to address health informatics and bioinformatics capacity in Wales and consider the future alignment of funding to meet this strategic agenda
 - NISCHR will work with colleagues in the clinical research infrastructure and Local Health Boards to find adequate solutions to remove barriers for appropriate linkage of clinical records and genetic information
 - explore the support required to develop capacity for operational research and modelling, and facilitate collaboration between Health Boards and our academic strengths.



