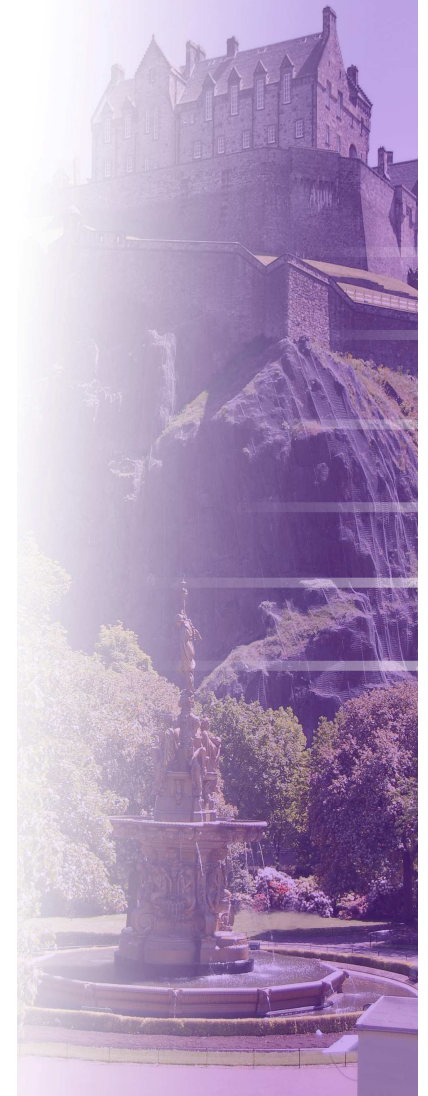


Edinburgh Health Service Research Unit

Welcome to our 2013 Update. Since our last report in November 2012, huge progress has been made, staff have become extremely busy and we are expanding our statistics team to meet demand. We have also welcomed our new administrator, Pamela Sinclair.

HSRU staff have contributed to 21 new research grants (p3) and 33 new peer-reviewed publications (p8). Some of these involve academic collaborations, some are addressing problems identified by the clinical services.

Ongoing work to develop research capacity and capability amongst nurses, midwives and allied health professionals is reported on p4, and the Unit is leading the South East Scotland contribution to two major research infrastructure initiatives. These are the SHARE Scottish research volunteer register (P6) and the development of a national network of data safe havens to provide secure access to de-identified health records for research (P5)



Asthma

HSRU staff have been involved in making a successful application to Asthma UK under the leadership of Prof Aziz Sheikh, to produce estimates of prevalence and costs of illness of asthma, separately for all the four nations of UK and for UK as a whole, with collaborators from the four nations. Work is ongoing now to produce a report. This work will subsequently feed into creating an Asthma UK Observatory (AUKO), which is one of the strategic platforms of the new Asthma UK Centre for Applied Research (AUKCAR), awarded to University of Edinburgh, with Queen Mary University of London as a key partner, with a network of collaborators UK-wide by Asthma UK. HSRU staff have also been involved in a PhD studentship application to Asthma UK to study the prevalence and healthcare costs of co morbidities of asthma, which covers two strategic platforms of AUKCAR, namely AUKO and the UK Postgraduate Training Scheme for Asthma



Edinburgh Health Service Research Unit

Edinburgh Health Service Research Unit (HSRU) is built on alliances between NHS Lothian and the University of Edinburgh, Edinburgh Napier University and Queen Margaret University, with NHS funding from Health Sciences Scotland. We focus on research that will

*“advance the planning, provision, effectiveness and efficiency of health care services with the overall aim of improving the healthcare of the public through enhanced clinical and organisational practices and (both) health and public policy.” **

What can HSRU offer? Our experienced staff aim to promote and nurture health services research by supporting and advising research teams and clinical services and by providing expertise in project planning, grant applications, research methods, statistics, record linkage and health economics.

HSRU will support the NHS to provide evidence-based health services by:

- working with service planners, providers and academic groups to identify opportunities for research in the context of service redesign;
- supporting initiatives to increase local capacity and capability in health services research;
- seeking funding from national and international sources for research relevant to health service redesign;
- developing and support a critical mass of projects with particular emphasis on studies which could be developed into substantive research areas;
- promoting collaborative research with other national and international partners sharing a common theme.

We aim to achieve these objectives through collaborating with NHS services and academic research groups, providing expert advice and input at the research planning and grant application stage, partnering with research teams and providing specialist services such as health economics, statistics or record linkage for particular studies on a fee for service basis following substantive grant awards.

*(Shi, L. (2008) Health Services Research Methods (2nd edition) Baltimore: Thomson: Delmar Learning.

Recovery following a stay in critical care

Dr. Pam Ramsay's research (CARC Advanced Practitioner) focuses on recovery following critical illness which is associated with significant physical and psychosocial sequelae.

- RECOVER has characterised the patient population and existing rehabilitative provision, identified unmet need and is evaluating a novel rehabilitative package and strategy; a Generic Rehabilitation Assistant. If clinically and economically efficacious, this strategy will be developed for routine clinical practice.
- RELINQUISH is currently the largest qualitative study of recovery among this patient group. It has identified patients' informal support and healthcare needs at key stages in the recovery process. Preliminary findings include: inadequate hospital discharge planning; poor communication between hospital and community (e.g. timely provision of home adaptation and aids); the dearth of formal community support (e.g. from GPs) and the importance of family in negotiating recovery. The critical care research team intend to work together with hospital and community-based clinicians, patients and families to develop timely and meaningful solutions to identified issues.
- EPIC is a novel web-based, patient and family-focused resource to support recovery. It will provide information (e.g. on common morbidity), advice (e.g. on managing fatigue, accessing aids and benefits) and support (from healthcare professionals and other patients and families). EPIC will underpin the subsequent development of a complex telehealth intervention to facilitate ongoing rehabilitation in patients' own homes and may incorporate an early supported discharge strategy.

Title: 4AT– A new tool to identify delirium. **Main Contact:** Alasdair McLulloch, University of Edinburgh. **Funder:** NIHR-HTA. **HSRU Contact:** Janet Hanley, Chris Weir **HSRU Contribution:** Statistics and qualitative component of study, JH and CW grantholders

Title: Identifying the true cost of asthma in the UK: secondary analyses of national stand-alone and linked **Main Contact:** Aziz Sheikh, University of Edinburgh **Funder:** Asthma UK **HSRU Contact:** Mome Mukherjee, Andrew Stoddart, Brian McKinstry **HSRU Contribution:** Study design, linked data analysis, cost analysis.

Title: Asthma UK Observatory - Working with the UK eHealth Informatics Centres of Excellence Network to obtain data enabling up-to-date monitoring of trends in key asthma outcomes. **Main Contact:** Aziz Sheikh, University of Edinburgh **Funder:** Asthma UK **HSRU Contact:** Mome Mukherjee **HSRU Contribution:** Availability of routine data.

Title: The relationship between premature birth and subsequent development of asthma in childhood. **Main Contact:** Jasper Been, University of Edinburgh **Funder:** Thrasher Fund **HSRU Contact:** Mome Mukherjee **HSRU Contribution:** Availability of routine data and possibility of linkage.

Title: Developing and validating measures of co-morbidity using Scottish routine datasets **Main Contact:** Professor Sarah Wild, University of Edinburgh **Funder:** CSO **HSRU Contact:** Chris Weir **HSRU Contribution:** Statistics

Title: Practical methods for meta-analysis of continuous outcomes in stroke rehabilitation trials **Main Contact:** Chris Weir **Funder:** Stroke Association **HSRU Contact:** Chris Weir **HSRU Contribution:** Leading this collaboration between University of Edinburgh, Glasgow Caledonian University, University of Glasgow

Title: Support for international community nursing conference in Edinburgh, **Main Contact:** Rebecca Nantondo, Eric Ezati, Reach Out HIV/AIDS Initiative, Kampala **Funder:** Mary McClymont Memorial Fund **HSRU Contact:** Rhona Hogg **HSRU Contribution:** Support with preparation of abstracts and funding application, setting up study tour

Title: User satisfaction with community nursing services **Main Contact:** Alison Jarvis, NHS Lothian **Funder:** NHS Lothian **HSRU Contact:** Rhona Hogg **HSRU Contribution:** Advice re: design

Title: Study to improve efficiency and effectiveness of occupational therapy services in NHS Lothian **Main Contact:** Susan Brown, NHS Lothian **Funder:** NHS Lothian **HSRU Contact:** Rhona Hogg **HSRU Contribution:** Advice re: qualitative methods

Title: Evaluation of day hospital, from perspectives of patients and health professionals **Main Contact:** Liz Adamson, Edinburgh Napier University **Funder:** Queens Nursing Institute of Scotland **HSRU Contact:** Rhona Hogg **HSRU Contribution:** advice re: research design and costings.

Title: Attitudes of young women to HPV vaccination in Serbia, Bulgaria and Scotland **Main Contact:** Carol Gray, Edinburgh Napier University **Funder:** Edinburgh Napier University (and institutions in Serbia and Bulgaria) **HSRU Contact:** Rhona Hogg **HSRU Contribution:** Co-investigator

Title: Does promoting increased awareness of decreased fetal movements reduce stillbirth, a stepped wedge cluster randomised trial **Main Contact:** Professor Jane Norman, University of Edinburgh **Funder:** Chief Scientist Office; Stillbirth and Neonatal Death Society **HSRU Contact:** Chris Weir **HSRU Contribution:** Statistics

Title: Phase 2 randomised trial of early versus delayed future care planning for patients with advanced heart disease **Main Contact:** Dr Martin Denvir, University of Edinburgh/ **Funder:** Marie Curie Cancer Care **HSRU Contact:** Chris Weir **HSRU Contribution:** Design; Statistics; Randomisation.

Title: Exploring the feasibility of using remote respiratory monitoring to detect and manage exacerbations of chronic obstructive pulmonary disease **Main Contact:** Brian McKinstry **Funder:** Chief Scientist Office **HSRU Contact:** Chris Weir, Janet Hanley, Brian McKinstry **HSRU Contribution:** Clinical Academic Lead; Statistics; Mixed methods.

Title: SHARE: The Scottish Health Research Register. **Main Contact:** Brian McKinstry **Funder:** Chief Scientist Office **HSRU Contact:** Janet Hanley, Brian McKinstry

Title: An exploratory study of the acceptability and perceived value of electronic multi-compartment medication devices to inform a subsequent RCT of their effect on medication adherence **Main Contact:** Brian McKinstry, Christine Bond **Funder:** Chief Scientist Office **HSRU Contact:** Brian McKinstry **HSRU Contribution:** Design, lead

Title: Exploring the feasibility of using remote respiratory monitoring to detect and manage exacerbations of chronic obstructive pulmonary disease **Main Contact:** Brian McKinstry, Roberto Rabinovich **Funder:** Chief Scientist Office **HSRU Contact:** Brian McKinstry, Janet Hanley **HSRU Contribution:** Design, lead

Title: PEGASO. Personalised Guidance Services for lifestyle management and Obesity prevention in teenagers. **Main Contact:** Rajeeb Rashid, NHS Lothian **Funder:** European Union **HSRU Contact:** Brian McKinstry, Janet Hanley **HSRU Contribution:** Design, lead clinical study

Title: Pilot study of the costs and benefits of follow-up appointments via videoconference for families and children with additional support needs **Main Contact:** Christine Owen, NHS Lothian **Funder:** Edinburgh and Lothians Health Foundation **HSRU Contact:** Andy Peters Brian McKinstry, Janet Hanley **HSRU Contribution:** Design and execution of study

Title: The use of Light-Touch Telemetry in the management of COPD **Main Contact:** Hilary Pinnock, University of Edinburgh **Funder:** Edinburgh and Lothians Health Foundation **HSRU Contact:** Brian McKinstry, Janet Hanley **HSRU Contribution:** Co-investigators

Title: Administration of eye drops for 'dry eyes' in rheumatoid arthritis **Main Contact:** Liz Adamson, Edinburgh Napier University **Funder:** Edinburgh Napier University **HSRU Contact:** Rhona Hogg **HSRU Contribution:** Advice re: design and ongoing support



Developing Research Capacity and Capability

CARC

Clinical Academic Research Careers



The CARC Scheme for Nurses, Midwives and Allied Health Professionals in NHS Lothian has been 'live' since January 2011. Four nurses have been employed in 0.5 wte posts via internal secondment arrangements – an Advanced Practitioner (post-doctoral level) and a Senior Practitioner (PhD study) in each of the Critical Care/University of Edinburgh and Substance Misuse/Edinburgh Napier University/University of Edinburgh demonstration sites. In October 2012 a successful bid from the Weight Management Service/Queen Margaret University/NHS24/ Edinburgh Napier University was funded, thereby establishing the final site. This team is currently in the process of recruitment to two Senior Practitioner posts (PhD study).

Progress in the Critical Care and Substance Misuse sites has been good. The post-holders in both have developed their research networks both nationally and internationally, presented at conferences, achieved journal publications, and (in the case of Critical Care) been awarded modest grants to further develop their research programme. Postholders in both sites are preparing further grant applications and journal submissions.



A team from the University of Worcester is currently conducting Phase 1 of the independent evaluation of the Scheme with the final report due in September 2013.

The objectives over the next 6 months include production of a discussion paper on the sustainability aspects of clinical academic research careers for NMAHPs in Lothian.

Lothian Nursing, Midwifery and Allied Health Professions (NMAHP) Research Framework: Progress and Achievements

There has been considerable progress and achievements in implementing the NMAHP Research Framework during the past year. These include:

Development of an innovative funding scheme to support early career researchers - Research Futures. This annual award funded by the Nursing and AHP Directorates totalling £35,000 will go towards supporting research interested NMHAPs to pursue either a PhD/ Masters in Research or to undertake a supervised research internship of up to 26 days with an established research team in NHS Lothian or partner higher education institution.



Introduction of the Midwifery Research Champions scheme known as the 'Midwifery and Obstetric Research Excellence' (MORE) involving the appointment of 6 midwives to support promotion of existing clinical trials and the development of midwifery research capacity. The scheme is funded by the R&D Office for an initial 12 month pilot to allow the midwives to work an additional 2 hours per week in this capacity.

Since the introduction of the scheme two of the midwives have been successful in being awarded PhD studentships at Edinburgh Napier University and will commence their studies in September 2013.



Developing Research Capacity and Capability

The Farr Institute and NHS Lothian Safe Haven

The Farr Institute is an MRC funded, UK wide collaboration involving 19 universities across the UK to develop the safe use of patient and research data for medical research across all diseases. It builds on the four e-health informatics research centres (HeRCs) recently funded by a consortium of three Research Councils, three health departments and four leading medical research charities, bringing the total investment to £39million.

Medical, population and computer scientists will combine their expertise to interpret large and complex health datasets in research environments that safeguard patient confidentiality. Researchers will develop methods for safely sharing, combining and analysing diverse datasets across boundaries, enabling new discoveries and validating research findings with a speed and scale not previously possible. The concentration of funding in developing UK health informatics research base will provide a focus for collaborations with IT and pharmaceutical companies, attracting inward investment into the UK economy.

The Institute's independent research will support innovation in the public sector and industry leading to advances in preventative medicine, improvements in NHS care and better development of commercial drugs and diagnostics. It will also provide new insights into the understanding of causes of ill health which in turn will guide new biomedical research discovery. In addition to health benefits for patients and UK citizens, the Institute will help to cement the UK's reputation as a world leader in research using large electronic health data.

The Scottish Centre, led by Professor Andrew Morris from Dundee, has a national UK wide network co-ordinating role. In addition to the existing accommodation in Dundee, it will develop a physical base in 9 Bio-quarter, Edinburgh where researchers from all participating institutions can work. The Farr institute will be underpinned by a network of NHS Safe Havens which will develop anonymised datasets based on patient records and provide access to them for Farr Institute and other researchers in a way which ensures that individual level data does not leave the NHS. The national safe haven and Electronic Data Research and Innovation Service (eDRIS) which is run by National Services Scotland Information and Statistics Division (ISD) will be based in the Farr Institute building in Edinburgh. NHS Lothian is working with University of Edinburgh to extend its safe haven facilities to support this initiative. The Lothian safe haven co-ordinator will be based in the Edinburgh Clinical Trials Unit (ECTU) offices at the Western General Hospital.

Edinburgh HSRU hosts study visit for Ugandan community nurses

Two senior Ugandan community nurses from Reach Out HIV/AIDS Initiative, Kampala, travelled to Edinburgh from Kampala in March 2013, to present their research at the International Collaboration of Community Health Nurse Research conference and to undertake a study tour of HIV/AIDS services in Scotland. The visit was organised by Dr Rhona Hogg, research lead for community nursing/ qualitative methods within Edinburgh Health Services Research Unit and funded by the Mary McClymont Memorial Fund. As well as their research papers, Rebecca Nantondo and Eric Ezati delivered the Mary McClymont Memorial lecture about Reach Out which delivers innovative holistic medical care to 4,500 HIV +ve clients living in three slum areas of Kampala, as well as a rural area north of Kampala. Reach Out also provides emotional, social and practical support to clients and orphaned and vulnerable children. During their two week visit to Edinburgh, Rebecca and Eric also met with NHS Lothian healthcare professionals, representatives of voluntary agencies and academics to share experiences and expertise.





Recruiting for Research, Improving our Health

The Scottish Health Research Register (SHARE) is a new [NHS Research Scotland](#) initiative created to establish a register of up to 1,000,000 adults (25% of the Scottish adult population) who consent to the access and use of their electronic health records in order to identify them as potentially eligible for research projects. SHARE will greatly enhance the efficiency and effectiveness of recruitment into health research projects in Scotland.

- The direct volunteer contact allowed by SHARE registration means that the assessment feasibility and contact process is both rapid and efficient.
- By gaining consent to contact people that have already expressed an interest in clinical research recruitment, retention rates can be enhanced.

In Scotland, because of "Cradle to Grave" data linkage, it is possible to interrogate clinical and administrative systems to identify people who match study inclusion and exclusion criteria.

SHARE is currently implementing an extensive recruitment programme that communicates with the Scottish public, encouraging them to join and also participate in clinical trials.

When a research team has a project, SHARE will carry out a feasibility forecast to determine an appropriate number and distribution of recruits are available. If this looks satisfactory SHARE volunteers will be contacted directly by the SHARE office to advise of a research opportunity. This contact uses brief materials developed and approved by the research team. Researchers can use the SHARE approach in combination with more traditional direct from clinician contact.

SHARE contacts for Lothian are

Ellen Drost - Ellen.drost@ed.ac.uk

Rebecca Skillen - Rebecca.skillen@nhs.net

www.registerforshare.org



Who does what in HSRU?

HSRU is a dispersed organisation with contact and planning maintained with monthly teleconferences/meetings. Dedicated HSRU staff (marked below by *) are accommodated within departments which will give them appropriate academic or clinical service support. Other staff contribute to the development and running of HSRU on a sessional basis or as part of their wider roles.

Due to considerable HSRU success in obtaining project funding from research councils and other national funding bodies (see Funded Studies section), and the ongoing commitment to provide co-applicant statistical and methodological support for these funded projects, we intend to supplement the HSRU team with the expertise of another senior statistician in order to be able to continue to support researchers who approach HSRU for guidance on developing collaborative research .

We are also in the process of appointing a full time co-ordinator for the Lothian safe haven (see article on The Farr Institute and NHS Lothian Safe Haven)

	Background/ role	Organisation/ link organisation	Role in HSRU
Brian McKinstry	General Practice	University of Edinburgh	Clinical Lead HSRU. Advice on trials design, recruitment, GP link
Janet Hanley	Nursing	NHS Lothian R&D/ Edinburgh Napier University	Research Portal, mixed methods research, qualitative research, ethics, governance; leads NHS team
Chris Weir*	Statistician	University of Edinburgh	Trial design, statistical methods
Rhona Hogg*	Public Health Nursing	NHS Lothian/ Edinburgh Napier University	Qualitative research, community nursing/ public health nursing research, evidence based practice
Juliet MacArthur	Nursing	NHS Lothian Nursing Directorate/University of Edinburgh	Leads the implementation of the NMAHP Research Framework, link with Nursing and NHS Quality Strategy
Andy Peters*	Clinical Psychology/ Allied Health Professions	NHS Lothian	Research capacity building in AHPs, leads and develops AHP research
Mome Mukherjee*	Senior Data Analyst	University of Edinburgh	Advice on availability of routine data and possibility of data linkages.
Joel Smith*	Health Economist	University of Edinburgh	Advice on health economics
Andy Stoddart*	Health economist	University of Edinburgh	Advice on health economics
Lorraine Smith	Operational Lead	Edinburgh Clinical Trials Unit	Leads operational and administrative team
Pamela Sinclair*	Administrator	Edinburgh Clinical Trials Unit	Minutes, project database.

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