





# **NHS** Lothian **R&D** Conference 2019

## 'Meeting NHS priorities through **Research and Innovation'**

#ACCORDConf19

Thursday 28th March 2019

at

Wellcome Auditorium, Queen's Medical **Research Institute, Little France Crescent, Edinburgh Bioquarter** 







Academic and Clinical Central Office for Research and Development



### Speakers

### Prof. Tim Walsh



### Director of Research & Innovation, NHS Lothian

Tim Walsh is Professor of Critical Care at Edinburgh University, Scotland and Honorary Consultant in Critical Care at Edinburgh Royal Infirmary, Edinburgh. He leads a multidisciplinary clinical research group with interests including transfusion medicine, sedation in the critically ill, recovery from critical illness and the epidemiology and prevention of ICU acquired infection. He is also currently Director of Research and Development for NHS Lothian, and a past Chairman of the UK Critical Care Research Network and UK Critical Care Research Group.

'Welcome and Introduction'

### **Mr Tim Davidson**



### **Chief Executive, NHS Lothian**

Tim Davison joined the NHS in Scotland as a graduate management trainee in 1983 and has been a member of the Institute of Healthcare Management since then. He has worked in all sectors of the NHS in Forth Valley, Greater Glasgow, Lanarkshire and Lothian Health Board areas. Tim was Chief Executive of the Greater Glasgow Community and Mental Health Services NHS Trust 1994-99, Chief Executive of the Greater Glasgow Primary Care NHS Trust 1999-2002, Chief Executive of the North Glasgow University Hospitals NHS Trust 2002-2005 and Chief Executive of NHS Lanarkshire from 2005 until 2012 when Tim took up his current position as Chief Executive of NHS Lothian.

'The Big Strategic Challenges for NHS Lothian – how can Research, Development & Innovation help?'













### **Mr Ricky Verrall**



### Head of Chief Scientist Office, Scottish Government

Ricky is a career civil servant who spent several years working for the UK Government in Whitehall before moving into the Scottish Government in 2003.

In his UK Government posts Ricky led on a range of policy issues including export promotion; EU product standards and testing policy; negotiation of product harmonisation Directives in Brussels; international trade negotiations in Brussels and Geneva; oil and gas licensing and related transboundary treaty negotiations with other North sea states; and UK strategy on energy security of supply.

Since joining the Scottish Government, Ricky has led policy teams to develop a strategy to protect Scotland's marine environment; headed the Health Workforce Planning and Development Division in the Health and Social Care Directorates; and led a programme of work on the structure and capacity of Government as part of the Scottish Government's preparations for the 2014 independence referendum.

Ricky returned to the Health and Social Care Directorates in March 2015 to lead a programme of work, including a participative public engagement process, on the future of health and social care in Scotland out to 2030. He was appointed as Head of the Chief Scientist Office in August 2016.

#### 'The Chief Scientists Office strategy for Research, **Development & Innovation'**

Against the background of "Delivering Innovation through Research" - the current Scottish Government health and social care research strategy - Ricky will give an overview of the role of the Chief Scientist Office, NHS Research Scotland and the Health Innovation Network in promoting and supporting R&D and innovation in health and care; set that work in a wider UK context; and outline how R&D and innovation involving the NHS and social care contribute to the Government's National Outcomes for both Scottish health improvement and sustainable economic growth.









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### **Prof. Gillian Mead**



### Professor of Stroke and Elderly Care Medicine, University of Edinburgh

### Background

•2000: Senior lecturer then Reader in Geriatric Medicine, and Honorary Consultant Geriatrician and Stroke Physician
•2012: Personal Chair in Stroke and Elderly Care Medicine
•2010: NIHR Ageing Specialty Group Lead for Scotland

Stroke is the major cause of severe adult disability. Gillian's research aims to find out how to improve recovery and quality of life of people who survive a stroke. She is trialling several treatments (including exercise and antidepressants) to find out whether they might improve quality of life and recovery from a stroke.

Gillian's research is driven by the clinical needs of patients. She employs a variety of research designs, including systematic reviews, observational studies, qualitative research methodology and randomised controlled clinical trials.

Her research is focused on the under-researched area of 'Life after Stroke'. Gillian leads programmes of research in fatigue, exercise and cognition after stroke; these topics are amongst the top 10 priorities for stroke research. She is co-principal investigator of the FOCUS Trial (Fluoxetine or control Under Supervision), a UK multicentre trial that seeks to determine whether fluoxetine improves recovery after stroke.

### 'Effects of fluoxetine on functional outcomes after acute stroke (FOCUS): a pragmatic, double-blind, randomised, controlled trial'

Stroke is a major cause of disability. Although there have been advances in the acute management of stroke, many survivors are left with significant disability. In 2012, a Cochrane review suggested that selective serotonin reuptake inhibitors might reduce disability after stroke-through mechanisms such as neuroprotection. Our team therefore established the large UK multicentre RCT of fluoxetine for stroke recovery. We recruited 3127 patients and demonstrated that, despite its early promise, fluoxetine had no effect on recovery after stroke. It reduced depression at follow-up but increased the risk of bone fractures. Compliance was around 70% and follow-up rate over 99%. In this talk, I will explore the trial design, methodology, and challenges that we faced, and what we learnt from the trial.













### **Prof. Alex McMahon**



### Executive Director, Nursing, Midwifery and AHP's, NHS Lothian

Alex is a registered mental health and general nurse. He has worked in senior positions in the NHS, private sector and government.

His current role is wide ranging and professionally covers all nurses, midwives and AHPs which is around 14,000 staff.

Alex is Chair of the Scottish Nurse Directors Group and also holds honorary chairs with Queen Margaret University and the University of Stirling.

Chair: 'Celebrating the Queen's Anniversary Award for **Research to Improve Women's Health'** 

### **Prof. Richard Anderson**



### Elsie Inglis Professor of Clinical Reproductive Science, **University of Edinburgh**

Appointed to a Consultant post in 1998 in the MRC Reproductive Biology Unit and at RIE, and to Chair of Clinical Reproductive Science at the University in 2005. He has established a group investigating female reproductive lifespan, with laboratory and clinical aspects particularly related to the adverse effects of cancer treatment on fertility.

### 'Taking fertility preservation from the lab to the patient and to the population'

Fertility preservation has now become 'mainstream medicine'. Freezing ovarian tissue for this started with animal experiments here in Edinburgh in the 1980's before being developed into an experimental clinical protocol. Since then it has spread around the world, and used for girls as well as adult women. Sperm cryopreservation has long been available for adult men: freezing testicular tissue is being explored for prepubertal boys. These approaches are now becoming established across NHS Scotland, to provide an effective and equitable service.











### **Dr Sarah Stock**



Wellcome Trust Clinical Career Development Fellow and Senior Clinical Lecturer/ Honorary Consultant and Subspecialist in Maternal Fetal Medicine, University of Edinburgh/NHS Lothian

Lothian

Sarah's research focuses on why some babies are born too early (preterm birth), and some die in the womb (stillbirth), and developing strategies to prevent this. She has a BSc from the University of St Andrews and went to Manchester University Medical School. During her PhD from the University of Edinburgh she studied host defence mechanisms to infection in pregnancy, and how these can prevent preterm birth. She continues to lead discovery science projects to identify new targets for preterm birth prevention, but also has a portfolio of clinical research studies aimed at reducing perinatal mortality and improving the health of babies and children. Sarah has recently been awarded a Wellcome Trust Clinical Career Development Fellowship and established the international Co-OPT collaboration to study the effects of preterm birth treatments on babies and children. She also work as a consultant and subspecialist in maternal fetal medicine, with training in Edinburgh, Glasgow, London and Australia. Sarah now leads Scotland's first preterm birth prevention clinic, and has regular specialist fetal medicine sessions.

### 'Reducing perinatal mortality - translational clinical research in pregnancy to prevent stillbirth and preterm birth'

### **Prof. Hilary Critchley**



### **Professor of Reproductive Medicine, University of Edinburgh**

Professor Hilary Critchley's research programme focuses upon local uterine/ endometrial mechanisms involved in menstruation, abnormal uterine bleeding and implantation. Her studies have informed development of novel treatment strategies for problematic uterine bleeding. Recent studies have included further development of models for studying menstruation and uterine/ endometrial bleeding. She has over 250 peer-reviewed publications.

She has Co-Chaired an International Agreement Process for terminologies /definitions and a classification system for abnormalities













of menstrual bleeding supported throughout by the International Federation of Gynecology and Obstetrics (FIGO). She is a Past-Coordinator of the European Society of Human Reproduction and Embryology (ESHRE) Special Interest Group Endometriosis & Endometrium. She is a current member of the University of Cambridge Centre for Trophoblast Research (CTR) Scientific Advisory Board; an immediate past Board member of the World Endometriosis Society (WES) and immediate past Board member of the Society for Endometriosis and Uterine Disorders (SEUD). Her expertise in the field of endometrial biology/ reproductive medicine has been nationally and internationally recognised. In 2009 she was elected to the Fellowship of The Academy of Medical Sciences (UK) and in 2012 she was elected to the Fellowship of The Royal Society of Edinburgh (Scotland's National Academy).

### 'Abnormal uterine bleeding: still an enigma and taboo, a challenge for clinical research'

Women nowadays may expect to menstruate over 400 times during their reproductive life span yet the topic of menstruation remains taboo. The withdrawal of circulating progesterone is the signal that triggers menstruation and following shedding (menses), the endometrium displays remarkable and immediate regenerative capacity. The precise local mechanisms involved in the control of the highly coordinated cyclical tissue 'injury' and 'repair' that occurs in the absence of a pregnancy have still to be fully elucidated. Modern molecular technologies and animal models of "simulated menstruation" have permitted an expansion of knowledge of mechanisms underpinning this pivotal event in human reproduction. Valuable insight about progesterone action and endometrial function has come from the observations of pharmacological withdrawal of progesterone from the endometrium. PR ligands such as the selective progesterone receptor modulators (SPRMs) offer new medical approaches to management of menstrual bleeding disorders. Improved precision of treatment of menstrual disorders requires characterisation of the aetiologies underlying the complaint. We have undertaken two clinical trials, both with their own challenges, which aim to identify new treatment approaches for an often debilitating complaint that affects 1 in 4 women, has major impacts upon the individual and imposes a socio-economic burden (DexFEM; UCON).













### **Prof. Alison McCallum**



### **Director of Public Health and Health Policy, NHS Lothian**

Director of Public Health & Health Policy NHS Lothian since 2005; Honorary Chair in Public Health, University of Edinburgh, Passionate about increasing equity, reducing premature death and taking a wider view. Local roles include: Executive Lead for R&D; NHS Lothian professional lead for dentistry and psychology; Caldicott Guardian (pro multiagency information sharing, register-based research, data linkage for research, practice and policy, keeping public trust, high quality analysis & archiving), National and international: Member of Public Benefits & Privacy Panel, Chair CHI Advisory Group, National Health Services Central Register Governance Board, Member UK Council of Caldicott Guardians; Co- Chair, Faculty of Public Health Europe Special Interest Group, WHO Europe Coalition of Partners Group.

History: Qualified in medicine from Glasgow, Public Health in North East England, Consultant and DPH, North London and Eastern Region/ Hon. Senior Lecturer in Royal Free /UCL, Public Health Specialist and Researcher National Institute of Health & Welfare in Finland.

### Chair: 'Research & Development: Improving Patient Care'

### **Dr Matthew Reed**



### Consultant and NRS Fellow in Emergency Medicine, NHS Lothian

Matt graduated from Cambridge University in 1997. He joined the South East Scotland Emergency Medicine Training Programme in 2002 and has been a Consultant in Emergency Medicine in Edinburgh since 2007. Matt is also an Honorary Reader with the Acute Care group of the University of Edinburgh.

After completing his Doctorate of Medicine thesis in 2009 on the risk stratification of syncope in the ED, Matt has continued research work in this area specifically focusing on the role of biomarkers in the prediction of adverse events after syncope and the use of novel ambulatory monitoring technology for the prediction of arrhythmia in syncope, pre-syncope and palpitations. He has published 90 peer reviewed papers as well as numerous conference presentations and has personally been awarded over £950,000 in research contracts/grants in his career.

Matt is Director and co-founder of EMERGE, a member of the RCEM Research and Publication Committee, chair of the RCEM grants committee, a member of the European Society of Cardiology Syncope Task Force and immediate past chair of the Scottish Transfusion and Support in Trauma Group and Royal Infirmary of Edinburgh Hospital Transfusion Committee.













### 'The IPED (Investigation of Palpitations in the ED) study'

This multi-centre open label, randomised controlled trial recruited participants  $\geq 16$  years old presenting to 10 UK hospital EDs with palpitations and pre-syncope and no obvious cause. Participants were randomised to either (a) intervention group; standard care plus a smartphone-based event recorder (AliveCor) or (b) control group; standard care alone. Primary endpoint was symptomatic rhythm detection rate at 90 days. 243 participants were recruited over an 18-month period. Use of a smartphone-based event recorder increased the number of patients in whom an ECG was captured during symptoms over five fold to more than 55% at 90 days (69/124; 55.6%; 95% CI 46.9-64.4% vs 11/116; 9.5%; 95% CI 4.2-14.8; RR 5.9, 95% CI 3.3-10.5; p<0.0001). The smartphone-based event recorder also decreased the mean time to symptomatic rhythm detection (9.5 vs 42.9 days) and increased the number of patients diagnosed with cardiac arrhythmia (11/124; 8.9%; 95% CI 3.9-13.9% vs 1/116; 0.9%; 95% CI 0.0-2.5%). A smartphone-based event recorder should be considered for all patients presenting to EDs with unexplained palpitations or pre-syncope. It is safe, non-invasive, easy to use and far more efficient at diagnosing the underlying cause than current standard care, which in the healthcare system studied does not serve this patient group well.

### Gemma Logan



### PhD Candidate / Staff Nurse, Centre for Person-centred Practice Research / Medicine of the Elderly, Queen Margaret University / NHS Lothian

Gemma Logan is currently undertaking a PhD at Queen Margaret University in collaboration with NHS Lothian focused on person-centred discharge of older people from the acute hospital. She also works part time as a Staff Nurse in a Medicine of the Elderly ward at the Royal Infirmary of Edinburgh.

Gemma began her career combining both clinical and academic/research pathways in 2014, undertaking a Masters in Nursing in Clinical Research at the University of Edinburgh and working as a Staff Nurse with older people. Following completion of the Masters, Gemma was appointed as a Research Nurse at the National CJD Research and Surveillance Unit in Edinburgh where she worked part time on a study to identify missed cases of Prion Disease in those aged 65 and over with atypical Dementia. Gemma worked here for a duration of three years, during which time she also became the Principal Investigator for a qualitative study exploring care home discharge decision-making. Gemma commenced her PhD in 2018.













Gemma's clinical and research interests include older people, acute hospital discharge and person-centred practice.

### 'One chance to get it right: Exploring perspectives on decisionmaking for discharge to care home'

Discharge from acute hospital to care home is a complex and life changing process. This study aimed to explore the perspectives of key stakeholders who contribute to decision-making about discharge to care home.

A case study research design was used to explore the experiences of six people admitted to hospital from home for whom discharge to care home was planned. Each dataset included semi-structured interview data from a person, their significant others and multidisciplinary professionals involved in their care (n=30). Ward case notes and social work records were also reviewed.

Grounded in practice, this study has the potential to lead to effective, collaborative and person-centred practice to improve the care of people making this decision. This presentation will discuss the study findings with emphasis on the implications for multidisciplinary health and social care practice.

### **Carol Porteous**



### PPI Advisor, Edinburgh CRF, NHS Lothian / University of Edinburgh

Carol is the PPI Advisor for the Edinburgh CRF, she is an experienced qualitative researcher and patient public involvement expert having worked in the area for over 12 years.

She has held a variety of positions including Public Engagement Lead for the Research Design Service London, based at King's College London and working on clinical trials at Moorfields Eye Hospital's Biomedical Research Centre. More recently she has been working on patient and public engagement in data linkage with the Farr Institute and the Administrative Research Centre Scotland, specifically looking at issues of public trust and acceptability of administrative data use in the health and social sciences.

### 'How to successfully embed PPI in Research?'

Carol will be joined by Kareen Darnley, Senior Research Nurse, Edinburgh CRF; and Stacey Stewart, Cardiology Research Nurse, Centre for Cardiovascular Sciences to present this talk.













### Dr Sandeep Ramalingam Consultant Virologist, Department of Laboratory Medicine, NHS Lothian



Dr. Sandeep Ramalingam is a Consultant Virologist at the Royal Infirmary of Edinburgh and also an Honorary Clinical Senior Lecturer at the University of Edinburgh.

After undergraduate studies in Medicine at Coimbatore Medical College, he did his MD in Microbiology and PhD in Virology at the Christian Medical College Hospital, Vellore, India. He worked at Kings College Hospital and Centre for Infections, Health Protection Agency, (Colindale) in London towards his FRCPath. He moved to Edinburgh in 2008.

His interests include identifying and augmenting innate antiviral mechanisms to clear viral infections. The work has led to the identification of a chloride ion dependent innate antiviral mechanism in non-myeloid cells (presented as a poster). This is the basis underlying the pilot randomised controlled trial (RCT) of hypertonic saline nasal irrigation and gargling in adults with a common cold which is being presented here (www.elvisstudy.com) and also for the larger RCT of hypertonic saline nose drops in children with an upper respiratory tract infection that is currently progress in (www.elviskids.co.uk).

### 'A pilot, open labelled, randomised controlled trial of hypertonic saline nasal irrigation and gargling for the common cold'

There are no antivirals to treat viral upper respiratory tract infection (URTI). Since numerous viruses cause URTI, antiviral therapy is impractical. As we have evidence of chloride-ion dependent innate antiviral response in epithelial cells, we conducted a pilot, non-blinded, randomised controlled trial of hypertonic saline nasal irrigation and gargling (HSNIG) vs standard care on healthy adults within 48 hours of URTI onset to assess recruitment (primary outcome). Acceptability, symptom duration and viral shedding were secondary outcomes. Participants maintained a symptom diary until well for two days or a maximum of 14 days and collected 5 sequential mid-turbinate swabs to measure viral shedding. The intervention arm prepared hypertonic saline and performed HSNIG. We recruited 68













participants (2.6 participants /week; November 2014-March 2015). A participant declined after randomisation. Another was on antibiotics and hence removed (Intervention: 32, Control: 34). Follow up data was available from 61 (Intervention:30, Control:31). 87% found HSNIG acceptable, 93% thought HSNIG made a difference to their symptoms. In the intervention arm, duration of illness was lower by 1.9 days (p = 0.01), over-the-counter medications (OTCM) use by 36% (p = 0.004), transmission within household contacts by 35% (p = 0.006) and viral shedding by  $\ge 0.5 \log 10/day$  (p =*0.04*). We hence need a larger trial to confirm our findings.

### **Andy Peters**



### AHP Research & Development Facilitator, NHS Lothian

In his NHS Lothian R&D post Andy has responsibility for the development of research capacity and capability among the Allied Health Professions. He also oversees the support and networking arrangements and system of annual activity review for 60+ NRS Fellows and NRS Clinicians in Lothian who receive support for ringfenced research time in their job plans. Andy is a Clinical Psychologist by professional background with 20 years of previous clinical experience in mental health, primary care, and substance misuse service settings having received his first degree from the University of Birmingham and his MPhil from the University of Edinburgh. Recent research interests and publications include the validation of outcome measures and feasibility testing of brief interventions relating to functional mobility in older age.

### Chair: 'Selected Projects from NRS Fellows and Clinicians in Lothian'

### **Dr Milly Lo**



### Consultant Paediatric Intensivist / Hon. Reader and Research Lead for Paediatric Critical Care / NRS Career Research Clinician, Royal Hospital for Sick Children, Edinburgh

Having completed paediatric intensive care training in Edinburgh, Birmingham, and Melbourne (Australia), Dr. Lo returns to the Edinburgh's Royal Hospital for Sick Children Hospital in 2010 as a consultant paediatric intensivist and research lead.

Dr. Lo's research training included successful completion of a PhD degree (under Prof. Minns' supervision in Edinburgh) and post-











doctoral research training in Toronto (Canada) to better understand how life-threatening childhood brain trauma outcome is influenced by acute physiological insults, genetic, and biochemical factors. This research training prepared Dr. Lo for the role of Hon. Reader at the University of Edinburgh. Dr Lo's research focuses on employing datainformatics approach to big data generated from routine clinical care for research to improve patient treatments, outcome, and safety in the paediatric critical care setting.

Dr. Lo has established a significant record of success in securing research grants and awards (and has over £1 million awarded to-date). With the support of an NRS Career Research Fellowship in 2013, Dr. Lo has set-up and is leading a dynamic multi-disciplinary data-informatics improvement research group (IMPACT-ACE). In 2017, Dr. Lo became the first paediatric intensivist to be awarded a EU grant to establish and lead an international paediatric brain trauma data-informatics research initiative (KidsBrainIT).

## *'KidsBrainIT & IMPACT-ACE: Data Informatics Improvement Research in Paediatric Critical Care - Concept, Challenges, Co-ordination, and Future Collaborations'*

Much of the routine data generated during the provision of medical care is discarded rather than fully used to help clinicians improve treatments. Multi-centre 'intensive-care big-data' initiatives such as the adult BrainIT group have successfully improved adult brain trauma care with new research ideas and data-driven improvement interventions. No-one has previously attempted to setup a similar approach in children with brain trauma. With the support of a prestigious EU grant, I have successfully setup a new paediatric brain trauma 'big-data' initiative (KidsBrainIT) that uses high-quality bedside physiological data from patients recruited in 15 PICU in 5 countries to better understand the importance of bespoke management improvements (e.g. treatment of increased brain pressure from brain swelling). I am using KidsBrainIT as a proof-of-concept to demonstrate the benefits of data-intensive informatics in improvement research and to translate this concept into IMPACT-ACE 'Intensive-Share' that will ultimately improve patient care, safety and outcome in the broader critical-care setting and other medical specialities in the future. In this talk, I will summarise the challenges we have overcome using this research approach and the exciting collaborations we plan for the future.











### **Mr Steve Leung**

### Consultant Urological Surgeon, Western General Hospital

Lothian

Steve is a Consultant Urological Surgeon with a sub-specialty interest in renal cancer surgery. His clinical work comprises laparoscopic and open renal surgery. He is looking forward to commencing the robotic partial nephrectomy programme in May 2019. Steve is the renal cancer lead for the SCAN region and chair of the Uro-oncology MDT. Steve was awarded the 3 year NRS fellowship in 2015. His research aims for the fellowship focused on novel diagnostics in urological diseases and understanding the survivorship issues following a diagnosis of urological cancer. Steve is the Principal Investigator on several industry sponsored clinical trials as well as a number of NIHR portfolio trials.

### *'Resurrecting the role of urine cytology in bladder cancer surveillance'*

The value of urine cytology as a means of bladder cancer surveillance has diminished over the last decade. The sensitivity of the test has been reported to be as low as 30% for low grade tumours. Specificity remains high for high grade tumours, but this cohort of patients represent only 20-30% of all bladder cancer patients. This has led to many urology units abandoning the use of routine cytology for surveillance and only relying on cystoscopy.

This talk will highlight how using automated image analysis, machine learning and immunocytochemistry techniques can increase the diagnostic accuracy and value of urine cytology. This work may lead to the resurrection of a non-invasive, low cost test that could replace cystoscopy in the surveillance of bladder cancer.







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### Dr Gillian Knowles



### Nurse Consultant – Cancer, NHS Lothian

Lothian

Gillian Knowles is currently working as a Nurse Consultant in Cancer at the Edinburgh Cancer Centre. She was awarded a NHS Research Scotland (NRS) Career Researcher Fellowship (2014-2017) and NRS Clinician award (2017-current) with a focus on evaluating the late consequences of pelvic treatment in people treated for anal cancer and the impact on day to day life. She is also a member of the Consequences of Cancer Treatment Collaborative (CCaT), funded by Macmillan Cancer Support. This is a UK initiative to address the consequences of cancer treatment through research, service and educational innovations.

In her current post she runs a pelvic clinic for patients who have been treated with locally advanced rectal cancer and anal cancer and, in collaboration with her colleagues, has successfully established a service for patients presenting with metastatic cancer of unknown primary as part of a programme of service development work for acute oncology.

*Consequences of pelvic chemo-radiation in anal cancer – supporting recovery* 

### Dr Gourab Choudhury



### Consultant Respiratory Physician and Senior NRS Clinician, NHS Lothian

Dr Choudhury is currently working as a respiratory consultant in the Royal Infirmary of Edinburgh. He is also the clinical lead for COPD and the Respiratory Managed Clinical Network Lead in NHS Lothian and is a Senior NRS Fellow with the University of Edinburgh. Having worked with Professor MacNee in the past, he completed his Fellowship from the University of Edinburgh and is currently also leading the clinical translational research in COPD in Edinburgh. His research interests lie in investigating the phenotypes of COPD and understanding the therapeutic options to treat these phenotypes more optimally. His clinical interest lies in integrating and bringing uniformity to the primary and secondary care pathways to effectuate the standard of COPD care and is currently involved in working in close conjunction with the Scottish Government to implement this uniformly across health boards.

'Role of Dynamic FDG PET imaging as a novel biomarker of lung inflammation in COPD'











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### NHS Lothian R&D Conference 2019 – Abstract for Oral Presentations

Presentation 1: Dr Matthew Reed	
Title:	Multi-centre randomised controlled trial of a smartphone-based event recorder alongside standard care versus standard care for patients presenting to the Emergency Department with palpitations and pre-syncope: the IPED (Investigation of Palpitations in the ED) study
Authors:	Matthew J Reed <sup>*1,2</sup> , Neil R Grubb <sup>3</sup> , Christopher C Lang <sup>3</sup> , Rachel O'Brien <sup>1</sup> , Kirsty Simpson <sup>1</sup> , Mia Padarenga <sup>1</sup> , Alison Grant <sup>1</sup> , Sharon Tuck <sup>4</sup> , Liza Keating <sup>5</sup> , Frank Coffey <sup>6</sup> , Lucy Jones <sup>7</sup> , Tim Harris <sup>8</sup> , Gavin Lloyd <sup>9</sup> , James Gagg <sup>10</sup> , Jason E Smith <sup>11</sup> , Tim Coats MD <sup>12</sup>
Affiliations:	<ul> <li><sup>1</sup> Emergency Medicine Research Group Edinburgh (EMERGE), Royal Infirmary of Edinburgh, UK</li> <li><sup>2</sup> Edinburgh Acute Care, Usher Institute, University of Edinburgh, UK</li> <li><sup>3</sup> Department of Cardiology, Royal Infirmary of Edinburgh, UK</li> <li><sup>4</sup> Edinburgh Clinical Research Facility, University of Edinburgh, Western General Hospital, UK</li> <li><sup>5</sup> Emergency Department, Royal Berkshire NHS Foundation Trust, Reading RG1 5AN, UK</li> <li><sup>6</sup> Nottingham University Hospitals NHS Trust, Nottingham, NG7 2UH, UK</li> <li><sup>7</sup> Chesterfield Royal Hospital NHS Foundation Trust, UK</li> <li><sup>8</sup> Barts Health NHS Trust, Whitechapel, London, E1 1BB, UK</li> <li><sup>9</sup> Royal Devon and Exeter Hospital, Barrack Rd, Exeter EX2 5DW, UK</li> <li><sup>10</sup> Department of Emergency Medicine, Musgrove Park Hospital, Taunton, TA1 5DA, UK</li> <li><sup>11</sup> Emergency Department, University Hospitals Plymouth NHS Trust, Plymouth, PL6 8DH, UK</li> <li><sup>12</sup> Emergency Medicine Academic Group, University of Leicester, Leicester, LE1 7RH, UK</li> <li><u>Corresponding Author</u>; Dr Matthew J Reed. Emergency Medicine Research Group Edinburgh (EMERGE), Department of Emergency Medicine, Royal Infirmary of Edinburgh, 51 Little France Crescent, Edinburgh, EH16 4SA, UK; Tel: 0131 242 1448; E-mail address: <u>matthew.reed@nhslothian.scot.nhs.uk</u></li> </ul>

**Aims:** Patients with palpitations and pre-syncope commonly present to Emergency Departments (EDs) but underlying rhythm diagnosis is often not possible during the initial presentation. This trial compares the symptomatic rhythm detection rate of a smartphone-based event recorder (AliveCor) alongside standard care versus standard care alone, for participants presenting to the ED with palpitations and pre-syncope with no obvious cause evident at initial consultation.

**Methods:** Multi-centre open label, randomised controlled trial. Participants ≥16 years old presenting to 10 UK hospital EDs were included. Participants were randomised to either (a) intervention group; standard care plus the use of a smartphone-based event recorder or (b) control group; standard care alone. Primary endpoint was symptomatic rhythm detection rate at 90 days. Trial registration number NCT02783898 (ClinicalTrials.gov).

**Results:** 243 participants were recruited over an 18-month period. A symptomatic rhythm was detected at 90 days in 69 (n=124; 55.6%; 95% CI 46.9-64.4%) participants in the intervention group versus 11 (n=116; 9.5%; 95% CI 4.2-14.8) in the control group (RR 5.9, 95% CI 3.3-10.5; p<0.0001). Mean time to symptomatic rhythm detection in the intervention group was 9.5 days (SD 16.1, range 0-83) versus 42.9 days (SD 16.0, range 12-66; p<0.0001) in the control group. Commonest symptomatic rhythms detected were sinus rhythm, sinus tachycardia and ectopic beats. A symptomatic cardiac arrhythmia was detected at 90 days in 11 (n=124; 8.9%; 95% CI 3.9-13.9%) participants in the intervention group versus 1 (n=116; 0.9%; 95% CI 0.0-2.5%) in the control group (RR 10.3, 95% CI 1.3-78.5; p=0.006).













**Conclusions:** Use of a smartphone-based event recorder increased the number of patients in whom an ECG was captured during symptoms over fivefold to more than 55% at 90 days. This safe, non-invasive and easy to use device should be considered part of on-going care to all patients presenting acutely with unexplained palpitations or pre-syncope.

**Funding:** This study was funded by research awards from Chest, Heart and Stroke Scotland (CHSS) and British Heart Foundation (BHF) which included funding for purchasing the devices. MR was supported by an NHS Research Scotland Career Researcher Clinician award.

Presentation 2: Gemma Logan	
Title:	One chance to get it right: Exploring perspectives on decision-making for discharge to care home
Authors:	Ms Gemma Logan, PI/PhD Candidate/Staff Nurse <sup>1,2,</sup> , Dr Jennifer K Burton, Clinical Lecturer <sup>3</sup> , Dr Sarah Rhynas, Lecturer <sup>4</sup>
	Other contributors:
	<ul> <li>Dr Juliet MacArthur, Chief Nurse for Research and Development<sup>2</sup></li> </ul>
	• Dr Susan Shenkin, Lecturer and Honorary Consultant in Geriatric Medicine <sup>2, 4</sup>
	• Professor Alasdair MacLullich, Professor of Geriatric Medicine and Honorary Consultant in General and Geriatric Medicine <sup>2</sup>
	<ul> <li>Professor Brendan McCormack, Head of the Division of Nursing/Associate Director, Centre for Person-centred Practice Research<sup>1</sup></li> </ul>
Affiliations:	<sup>1</sup> Queen Margaret University, <sup>2</sup> NHS Lothian, <sup>3</sup> University of Glasgow, <sup>4</sup> University of Edinburgh

**Aim:** Discharge from acute hospital to care home is a complex and life changing process. Previous work found variation in documented discharge practice and identified the complexity of the patients involved (Harrison et al., 2017). This study aimed to explore the perspectives of key stakeholders who contribute to decision-making about discharge to care home.

**Methods:** A case study research design was used to explore the experiences of six people admitted to hospital from home for whom discharge to care home was planned. Each dataset included semi-structured interview data from a person, their significant others and multidisciplinary professionals involved in their care (n=30). Ward case notes and social work records were also reviewed. Each dataset was analysed using an inductive thematic approach before cross dataset analysis.

**Results:** Discharge from hospital to care home was found to be a fragmented process. Professionals were uncertain about the processes involved resulting in disjointed communication and reluctance to engage with patients. A professional division of roles and responsibilities was evident, and social workers were perceived as separate from the ward team. Patients were keen to talk about, and rationalise their decision-making. Family members highlighted the complexity of balancing risk and care needs. The significance of the decision to the individual and their family was often not reflected in professionals' responses. The hospital context had the potential to facilitate decision-making in practical ways and in permitting conversations about care needs/wishes.













Conclusion: Exploring the perspectives of key stakeholders who contribute to decision-making about discharge to care home has offered a valuable opportunity to gain in-depth insights into the complexity of this process. The findings have reaffirmed that this is a life changing decision requiring greater recognition by care professionals. Professionals need to improve their understanding of care home discharge processes and recognise a shared responsibility for supporting those involved. Discharge practice should be person-centred, acknowledging individual circumstances, preferences, and holistic needs. Improved communication is central to enhance the experience of older people and their families during decision-making.

Grounded in practice, this study has the potential to lead to effective, collaborative and person-centred practice to improve the care of people making this decision. This presentation will discuss the study findings with emphasis on the implications for multidisciplinary health and social care practice.

Reference: Harrison JK, Garcia Garrido A, Rhynas SJ, Logan G, MacLullich AMJ, MacArthur J, Shenkin S (2017) New Institutionalisation following acute hospital admission: a retrospective cohort study, Age & Ageing, 46 (2): 238-244

Presentation 3: Carol Porteous, Kareen Darnley & Stacey Stewart	
Title:	How to successfully embed PPI in Research?
Authors:	Carol Porteous <sup>1</sup> , Kareen Darnley <sup>2</sup> & Stacey Stewart <sup>1</sup>
Affiliations:	<sup>1</sup> University of Edinburgh, <sup>2</sup> NHS Lothian

Aims: Patient and Public Involvement (PPI) in Research is advocated as a means of improving the quality and applicability of research and indeed is now a requirement of many funders. But how do we ensure that researchers across NHS Lothian are carrying out PPI to; support their research, to make their research relevant to patients, and to instil and embed this culture change in research across NHS Lothian? There are many good practice, guides, training and models of PPI in research. In NHS Lothian several models have been developed to support PPI in research, the PPI Champion model was developed with the aim to raise awareness across NHS Lothian of the multiple different uses and benefits that PPI can have in clinical research. The model enabled time, resource, education and support to be provided to local 'champions' to deliver a PPI project specific to their department / area of research. A further aim was to start a network to share and develop ideas. By inspiring and developing these individuals, the ultimate objective is to increase the capacity of PPI advocates across the region and to cascade their passion and skills to others.

By exploring the progress of two PPI Champions and their projects, the aim is to demonstrate how a small investment can maximise the potential impact and the potential of the PPI Champions model to embed PPI in research across NHS Lothian.

Methods: There are 8 PPI Champions across NHS Lothian, two PPI Champions projects and the developments made as well as their individual journeys will be explored. By examining the progress of PPI Champions Kareen Darnley who has been building a PPI group to improve the patient experience in the CRF at the Western General Hospital and Stacey Stewart who has been building a cardiovascular patient group to help with research, the potential impact of the PPI Champions role for relatively small investment will be demonstrated.











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**Results:** As a result of the PPI champion scheme some groups have been able to set up their own panel, held their first meetings and involved the panel in some research activities such as reviewing grant applications, patient facing documents and sitting on trial steering committees. This has taken hard work and each PPI Champion has been on a journey to build their PPI Champions role with support and training from the PPI service in Edinburgh CRF. Using Stacey and Kareen's' journeys; the challenges and opportunities of the PPI Champions model will be explored including the opportunities for:

- capacity building
- career development
- personal development
- improving research quality and patient experience of research and;
- the championing of PPI in research

The PPI service in Edinburgh CRF has been able to increase the breadth of PPI activity undertaken in Lothian through the development of a PPI Champion role, embedding PPI in research.

**Conclusion:** The projects are due for completion in Spring/Summer 2019, when it is anticipated that the champions will be embedded within their teams and working on plans to sustain their PPI activities. It is hoped that this initiative will promote a continued growth in the awareness of PPI in clinical research with patients and clinical teams across NHS Lothian.

Presentation 4: Dr Sandeep Ramalingam	
Title:	A pilot, open labelled, randomised controlled trial of hypertonic saline nasal irrigation and gargling for the common cold
Authors:	Sandeep Ramalingam <sup>1</sup> , Catriona Graham <sup>2</sup> , Jenny Dove <sup>1</sup> , Lynn Morrice <sup>3</sup> & Aziz Sheikh <sup>3</sup>
Affiliations:	<sup>1</sup> Department of Laboratory Medicine, Royal Infirmary of Edinburgh; <sup>2</sup> Wellcome Trust Clinical Research Facility, University of Edinburgh; <sup>3</sup> Centre of Medical Informatics, Usher Institute of Population Health Sciences and Informatics, The University of Edinburgh.

**Aims:** Viral upper respiratory tract infections (URTI), are very common and have a significant impact on individuals and the economy. Indirect clinical and lab evidence suggests that hypertonic saline nasal irrigation and gargling (HSNIG) may improve clinical and virological outcomes. We designed a pilot randomised controlled trial (RCT) to assess the feasibility of a larger RCT with efficacy end points.

**Methods:** Adults (>16 years) within 48 hours of URTI were randomised into intervention and control arms minimised by sex/smoking status. Those with symptoms >48 hours; chronic illness, allergic rhinitis, immunosuppression; pregnant; on antibiotics; or unable to perform HSNIG were excluded. Participants in the intervention arm were taught to prepare hypertonic saline (HS) with Cornish sea salt and perform HSNIG under observation. The highest comfortable concentration of HS was ascertained (1.5%-3.0%). The control arm received usual care. Both arms collected a baseline mid-turbinate (MT) swab in eNAT medium (Copan) to detect viruses. To measure change in viral shedding MT swabs were collected first thing in the morning on days1-4. WURSS-21, a validated symptom diary, was maintained up to 14 days or until they were well for two days or needed medical attention. Day o samples were tested by our respiratory panel (17 agents). If an agent was identified, all samples (day o - day 4) were tested in parallel and the cycle threshold value converted to log10 values to determine change in viral shedding. Recruitment was the primary outcome; sample











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return/diary completion, compliance, acceptability, quality-of-life, symptom duration and viral shedding were secondary outcomes. Ethical permission was obtained from the South East Scotland Research Ethics Committee 02 (REC Reference: 13/SS/0079). The study was registered in ClinicalTrials.gov (NCT02438579).

**Results**: Between November 2014-March 2015, 68 participants were recruited (average 2.6 participants/week). A participant declined after randomisation. Another was on antibiotics and hence removed (Intervention: 32, Control: 34). Baseline characteristics were similar between arms. Follow up data was available from 61 (Intervention: 30, Control: 31). 87% found HSNIG acceptable, 93% thought HSNIG made a difference to their symptoms. A virus was identified in 73% (48/66) of participants, (rhinovirus 56%; coronaviruses 31%). There was no difference between arms in returning diaries/swabs.

In the intervention arm, duration of illness was lower by 1.9 days (p = 0.01), over-the-counter medications (OTCM) use by 36% (p = 0.004), transmission within household contacts by 35% (p=0.006) and viral shedding by  $\ge 0.5 \log 10/day$  (p = 0.04). There was also a significant reduction in the duration of runny nose (1.8 days, 95% CI:0.4 to 3.2, p = 0.01), blocked nose (2.7 days, 95% CI:1.2 to 4.1, p < 0.001), sneezing (1.5 days, 95% CI:0.3 to 2.9, p = 0.02), cough (2.4 days, 95% CI:0.9 to 4.0, p = 0.003), hoarseness of voice (1.7 days, 95% CI:0.2 to 3.1, p = 0.02).

**Conclusions:** This pilot has demonstrated our ability to recruit and retain participants, and the acceptability of HSNIG. The significant reductions in duration of symptoms, symptom severity, over-the-counter medication use and illness within households and viral shedding indicate that this low cost intervention is effective against the common cold. The reduction in viral shedding is also in keeping with the antiviral effect seen in the presence of NaCl (Abstract submitted). Based on the above findings, we are now conducting a larger definitive trial in children called ELVIS Kids.













### NHS Lothian R&D Conference 2019 – Abstract for Poster Presentations

Poster Abstract 1	
Title:	Ultrahonix: Using ultrasound visual biofeedback for the treatment of speech sound disorders in children
Authors:	Joanne Cleland <sup>1</sup> , James M.Scobbie <sup>2</sup> , Zoe Roxburgh <sup>3</sup> , Cornelia Heyde <sup>2</sup> & Alan Wrench <sup>4</sup> .
Affiliations:	<sup>1</sup> University of Strathclyde, <sup>2</sup> Queen Margaret University, <sup>3</sup> NHS Grampian, <sup>4</sup> Articulate Instruments Ltd.

**Aims**: Ultrasound Tongue Imaging (UTI) is gaining popularity as a visual biofeedback tool for children with (especially persistent) Speech Sound Disorders (SSDs). Using standard medical ultrasound, it is possible to image either a mid-sagittal or coronal view of the tongue in real-time, providing learners with a "knowledge of performance" that enables them to correct in-error speech sounds. The evidence for Ultrasound visual biofeedback (U-VBF) therapy is small but promising, with around 30 published case or small group studies.

This study aimed to establish the effectiveness of ultrasound visual biofeedback (U-VBF) for children in Scotland with a wider variety of speech errors than previously reported. We hypothesised that U-VBF would show improvements in speech outcomes for a range of disorders affecting lingual speech.

**Methods**: Participants were 20 children aged 6 to 15 with SSDs recruited from NHS Lothian. Of these, fifteen children completed the intervention. All of the children presented with a variety of errors. We therefore employed a target selection strategy to treat the most frequent lingual error. A single-subject multiple (3) baseline design, with untreated wordlists was employed. Ultrasound was recorded synchronously with audio and used to review dynamic information about the children's speech errors for diagnostic purposes. Each child received 10-12 sessions of U-VBF with each child required to perform at 80% accuracy at each level of performance before moving on to a motorically more demanding level (for example, from single syllable words to disyllabic words). Analyses comprised narrow transcription of wordlists, calculation of percentage targeted segments correct and calculation of Standard Mean Difference.

**Results**: Six children were treated for velar fronting; three for post-alveolar fronting; two for backing alveolars to pharyngeal or glottal place; one for debuccalisation (production of all onsets as [h]); one for vowel merger; and two for lateralised sibilants. Ten achieved the new articulation in the first or second session of intervention despite no children being readily stimulable for their target articulation before intervention. In terms of generalization, effect sizes for percentage target segments correct ranged from no effect (five children); small effect (one child); medium effect (four children) and large effect (five children).

**Conclusion**: Ultrasound visual biofeedback can be used to treat a wide range of lingual errors in children with various speech sound disorders, from mild to severe. Visual feedback may be useful for establishing new articulations; however, generalization is more variable.













Poster Abstract 2	
Title:	Diagnostic yield of an ambulatory patch monitor in patients with unexplained syncope after initial evaluation in the Emergency Department: The PATCH-ED study
Authors:	Matthew J Reed * 1,2, Neil R Grubb 3, Christopher C Lang 3, Alasdair J Gray 1,2, Kirsty Simpson 1, Allan MacRaild 1,2, Christopher J. Weir 4
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	E-mail address: <u>matthew.reed@nhslothian.scot.nhs.uk</u>

**Aims:** Diagnosing underlying arrhythmia in Emergency Department (ED) syncope patients remains problematic. This study investigates diagnostic yield, event prevalence, patient satisfaction and compliance, and influence on resource utilization of an ambulatory patch monitor in unexplained ED syncope patients.

**Methods:** Prospective pilot study conducted in a single tertiary ED in Scotland between November 17th, 2015 and June 16th, 2017 with a historical unmatched comparator group. Patients 16 years or over presenting within 6 hours of unexplained syncope were fitted in the ED with an ambulatory patch ECG recorder (Zio® XT monitor), which continuously records a single lead ECG for up to 14 days. Patients with an obvious underlying cause were excluded. An unmatched historical group of 603 syncope patients with no obvious diagnosis in ED, recruited to a prior cohort study (2007-2008), were used as a comparator. Primary endpoint was symptomatic significant arrhythmia at 90-day follow-up.

**Results:** During the prospective study period, 86 patients were recruited. 90-day diagnostic yield for symptomatic significant arrhythmia was 10.5% (95% CI 4.0-16.9; 9 of 86) *vs.* 2.0% (95% CI 0.9-3.1; 12 of 603) in the comparator group. 24 patients (27.9%) had a significant arrhythmia (5 serious); 26 patients (30.2%) had serious outcomes (Major Adverse Cardiac Event and/or death). Blinded patch report review suggested the patch would significantly reduce requirement for standard outpatient ambulatory ECG monitoring. 56 of 76 returned patches had a diagnostic finding within +/- 45 seconds of a triggered/diary event (73.7% diagnostic utility; 95% CI 63.7-83.6); 34 of 56 (61%) for sinus rhythm or ectopic beats only.

**Conclusions:** Routine, early ambulatory ECG monitoring in ED patients with unexplained syncope is probably warranted. A large scale trial comparing this approach to standard care with cost effectiveness and safety analysis is now required.

Trial Registration: ClinicalTrials.gov Identifier NCT02683174













**Funding:** This study was funded by a minor research award from Chest, Heart and Stroke Scotland ( $\pounds$ 4,950). MR was supported by an NHS Research Scotland Career Researcher Clinician award. iRhythm Technologies, Inc. provided the Zio® XT monitors and ECG analysis service free of charge. CJW was supported in this work by NHS Lothian via the Edinburgh Clinical Trials Unit. iRhythm Technologies, Inc. and the funder had no involvement in the design, conduct, analysis or reporting of the study.

Poster Abstract 4	
Title:	Advanced Physiotherapy Practitioner consultation as an alternative to GP consultation for patients with Musculoskeletal Conditions in Midlothian
Authors:	Debbie Crerar, Lead Physiotherapist, Midlothian HSCP
Affiliations:	NHS Lothian

General Practice is currently experiencing considerable capacity and sustainability challenges. With General Practice carrying out 90% of patient contacts in the NHS and musculoskeletal (MSK) conditions accounting for 10 - 30% of GP appointments it is essential to explore new ways of coping with this demand.

In Midlothian, half the practices were operating with restricted lists as a result of increasing demand: a demand which is predicted to quickly rise as the influx of new housing has resulted in Midlothian being the fastest growing local authority area in Scotland.

The role of MSK Advanced Physiotherapy Practitioner (APP) within General Practice has been explored across the UK and it is now widely recognised that MSK APPs can successfully work within practice teams for patients experiencing musculoskeletal conditions.

**Aims:** The strategic principle of this work is to redirect appropriate patients from General Practice to MSK APP services with the aim of:

- improving GP capacity
- giving longer appointments to patients
- improving the patient pathway
- being cost effective and efficient
- allowing patients quick and easy access to highly specialised musculoskeletal input
- reducing referrals to secondary care, helping throughput and improving the conversion rate to surgery.

**Methods:** We will present a retrospective analysis of our first year of work, using both quantative and qualitative data.

**Results:** The full data for Year 1 is not yet available.

This service started in March 2018 and is now operational in five Midlothian practices, with the aim to expand to 7 practices in January 2019.

In the first six months the MSK APP service has had 1,289 appointments booked. Over 90% of the patients seen were managed by the MSK APP with no onward referral or follow-up required. 47.1% of patients using the service accessed it without seeing the GP first for the same problem. 1.3% were referred for an orthopaedic opinion. 3% required further investigation. Almost 203 hours of GP workload was redirected to physiotherapy. Early patient feedback is excellent.

**Conclusion:** MSK APPs can successfully work within General Practice as an alternative to a GP for patients with musculoskeletal conditions.











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Poster Abstract 5	
Title:	The PHQ-9 as a tool to measure depression in people with multiple sclerosis: a cross section validation study.
Authors:	S. Quigley, E. Beswick, P.Macdonald, P.Connick
Affiliations:	Centre for Clinical Brain Sciences, University of Edinburgh

**Background:** Depression has a point prevalence of 25% and lifetime prevalence of 50% in people with MS (pwMS). It is associated with lower quality of life, greater levels of fatigue and reduced adherence to disease-modifying therapy in MS. Despite being treatable, depression remains underdiagnosed in pwMS. Due to its convenience, the PHQ-9 may be a useful tool in clinical practice for screening and monitoring of depression in pwMS. No data is currently available on the psychometric properties of PHQ-9 in pwMS with respect to internal or external reliability, responsiveness, acceptability, and feasibility.

**Aims:** To evaluate the internal and external reliability of the PHQ-9 measure of depressive symptoms in people with MS. Secondary objectives are; to evaluate the validity of the PHQ-9 as a measure of depressive symptoms in people with MS, to evaluate the acceptability of the PHQ-9 to people with MS and to explore the responsiveness of the PHQ-9 as a measure of depressive symptoms in pwMS.

**Methods:** Patients with MS are currently being recruited from the Rowling Care registry at the Anne Rowling Regenerative Neurology Clinic. Patients complete three questionnaires during a 4 week period using online questionnaires. Cronbach's  $\alpha$  and the intraclass correlation coefficient will be used to measure internal and external reliability respectively. Convergent validity of the PHQ-9 will be evaluated by correlation with the psychological sub score of the MSIS-29.

**Results:** Recruitment is ongoing. There are currently 55 patients recruited to the study with a planned total recruitment number of 100.

**Conclusions:** The study is recruiting on the planned trajectory and we are projected to complete recruitment by the end of February 2019.











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Poster Abstract 6	
Title:	Attitudes towards pregnant women with substance use disorders – Proposal for a 3 stage study
Authors:	Dr Sonya MacVicar, Dr Naomi Waddell
Affiliations:	School of Health and Social Care, Edinburgh Napier University.

**Aims:** Substance use in pregnancy has an adverse impact on maternal and neonatal wellbeing and accessing specialist addiction/obstetric services is recommended. Yet this group record high rates of late booking in pregnancy, poor attendance and disengagement from services. One barrier cited for this is the fear of stigma and risk of being judged as a 'poor mother'. There is existing literature surrounding negative attitudes of health care practitioners within maternity and neonatal services towards women/new mothers with substance use disorders. The findings of the researcher's doctoral studies concur with this and further reveal a discord between HCPs perceptions of their behaviour and how it is perceived by those affected by substance use. This study aims to develop and psychometrically test the substance use disorder in maternity practice attitudes scale using a 3 stage approach.

#### Methods

Stage 1 – Undertake a mixed methods systematic review and narrative synthesis in order to explore the extant literature regarding the attitudes and behaviours of maternity/ neonatal healthcare professionals towards those affected by a substance use disorder. Stage 2 –develop an attitude scale which will explore, in-depth, the extent to which education, professional experience and personal attributes inform attitudes. Stage 3-psychometric test scale with health and social care students and practitioners within NHS Lothian.

Stage 1: A systematic search of CINAHL, MEDLINE, AMED, PsycArticles, PsycInfo and Web of Knowledge was undertaken in June 2018. Date limits of January 2007 to June 2018 were applied. Titles, abstracts and full papers were screened against inclusion criteria by two independent reviewers, who extracted and quality assessed data. Synthesis followed a thematic analysis approach.

**Results:** Stage 1 - Eight studies were included in the review. Negative attitudes towards pregnant women, partners and families affected by substance use disorders are pervasive amongst some maternity and neonatal practitioners. HCPs do not appear to consider their attitudes as judgemental or punitive. Education, length of experience and exposure to pregnant women/new mothers with SUDs appear to influence HCPs attitudes, however, the extent to which these and HCPs personal values and beliefs has not been fully explored to date.

**Conclusion:** A systematic review of the literature showed that negative attitudes exists within maternity services but practitioners do not perceive their actions or behaviours as recriminatory or judgemental. Negative attitudes may lead to self-censure amongst pregnant women/new mothers with SUDs, which may have detrimental impacts on the care and support of this vulnerable group. Further enquiry is required. Following the completion of Stage 1, Stage 2 will now be developed.









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Poster Abstract 7	
Title:	Practising realistic medicine in sever stroke: how can we support decision making regarding life-prolonging treatments?
Authors:	Akila Visvanathan <sup>1</sup> , Professor Martin Dennis <sup>1</sup> , Professor Julia Lawton <sup>2</sup> , Professor Gillian Mead <sup>1</sup> , Dr William Whiteley <sup>1</sup> , Dr Fergus Doubal <sup>1</sup>
Affiliations:	<sup>1</sup> Centre for Clinical Brain Sciences, University of Edinburgh, The Chancellors Building, 52 Little France Crescent, EH16 4SB
	<sup>2</sup> Usher Institute of Population Health Sciences and Informatics, Teviot Place, EH8 9AG

**Background and Aim:** Doctors discuss diagnosis and prognosis with patients and relatives to support them to make informed decisions regarding treatments. This is particularly important after severs stroke: treatments such as tube feeding and antibiotics are life-prolonging; i.e. they improve the likelihood of survival, but survival with substantial disability. Therefore, patients and relatives have to carefully weigh these trade-offs before making decisions.

We aim to develop a tool to deliver tailored information. This will be achieved by a mixed-methods study involving:

- a) Predicting recovery of specific functions after severe stoke e.g. mobility, speech
- b) Understanding patient and relative information needs to make treatment decisions and their views on survival and disability over time.

### Methods:

To answer (a):

- 1. Large trial data to build statistical models to predict recovery of functions (n=13117)
- 2. Recruitment of a longitudinal cohort to validate these predictions (n=403)

To answer (b):

1. Qualitative interviews involving sever stroke patients (n=15) and relatives (n=24)

**Results:** Specific functions can be predicted with reasonable accuracy (AUROC 0.7-0.8). We will validate this.

Patients and their relatives had different views. Patients looked for hope and wished positive news on their progress. They accepted all treatments in the hope to achieve functional recovery. Relatives often decided that life-prolonging treatments were not appropriate for the patient. Most looked for information on prognosis. Six months later, patients wished they had been given information on their prognosis. Most described valuing survival regardless of their disability. They preferred their doctor to have made treatment decisions for them. Relatives were content with their involvement in decision-making and did not think that the patient would value survival with disability.

**Conclusions:** We need to deliver tailored information to support treatment decision-making. I am developing a flexible tool: a slide set with multiple representations of information in accessible formats that clinicians can use to deliver personalised information. This may be printed or emailed. This tool will need further testing.











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Poster Abstract 8	
Title:	SCARF: <u>Supporting C</u> ommunity Recovery <u>a</u> nd Reducing <u>R</u> eadmission Risk <u>F</u> ollowing Critical Illness in ICU Survivors. From Research to Practice
Authors:	Eddie Donaghy & Jo Thompson
Affiliations:	University of Edinburgh

**Aim:** Survivors of critical illness experience multidimensional disabilities that include physical, psychological and cognitive decline, social challenges and reduced quality of life. This accumulation has been termed post-intensive care syndrome (PICS), with 25–30% requiring early unplanned hospital readmission within 90 days following index hospitalisation. Impact is also high for families/carers, especially in social and psychological domains. Post-ICU recovery programs have not been widely adopted or studied despite the scope of these problems. We aimed to investigate factors influencing early unplanned hospital readmissions and to develop and introduce a new integrated care pathway providing holistic, in-hospital assessment and facilitating improved multi-disciplinary community support for ICU survivors at risk of early unplanned hospital readmission.

**Methods:** As part of our mixed methods study to understand the complexity of ICU survivorship, and reasons for early unplanned hospital readmission within 90 days, we conducted in-depth

1-2-1 interviews and focus groups with ICU survivors (n=50) and families/carers (n=51). Learning from the research would inform the evidence-based development of a clinically and cost-effective intervention for a new ICU integrated care pathway in NHS Lothian. Following our research we secured funding for a 12 month Quality Improvement project funded by Health Improvement Scotland to introduce the new care pathway.

**Results:** For around half our patients a 'complex health & psychosocial needs' context occurred involving multi-morbidity, polypharmacy, significant psychological and mobility issues, problems with specialist aids/equipment and fragile social support prior to critical illness. These ICU survivors described inadequate preparation for hospital discharge, poor communication between secondary and primary care, and inadequate support with psychological care, medications and goal setting. Based on our research findings, we developed (i) an ICU holistic needs assessment tool to facilitate early identification of ICU survivors at risk of unplanned readmission; (ii) introduced in-hospital holistic needs assessment to identify clinical and psychosocial needs of 'at risk' ICU survivors; (iii) developed more holistic patient information summaries and quicker communication between ICU hospital assessment staff and GP's, community multi-disciplinary NHS locality Hubs, community pharmacies and third sector community social prescribing groups; (iv) initiated community follow up assessment of ICU survivors at 2 and 8 weeks after hospital discharge. We present case studies and evaluation data from our new anticipatory care pathway intervention highlighting improved holistic in-hospital assessment of ICU survivors. We highlight processes undertaken that facilitated quicker and better communication between hospital ICU staff, and GPs, NHS Lothian locality Hubs, community pharmacies and third sector community groups. We demonstrate benefits to ICU survivors and families/carers of the new integrated care pathway improving community recovery and reducing unplanned hospital readmission risk which is sustainable and transferable.

**Conclusions:** For many ICU survivors and their families discharge from hospital marks the beginning of what can be an arduous struggle. Targeted in-hospital holistic needs assessment and improved communication with community partners can facilitate community recovery and reduce readmission risk. These are the features necessary to achieve patient centred, cost-effective and integrated ICU follow-up care that improves long-term outcomes for ICU survivors.











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Poster Abstract 9	
Title:	Sedentary behaviour in stroke survivors: a qualitative study involving stroke survivors, caregivers and staff in two stroke services
Authors:	Sarah Morton <sup>2</sup>
	Presenting Author: Jennifer Hall <sup>1</sup>
	<b>Other authors</b> Morton S <sup>2</sup> , Fitzsimons C <sup>3</sup> , Mead G <sup>4</sup> , Hall JF <sup>1</sup> , Corepal R <sup>1</sup> , Clarke DJ <sup>1</sup> , Forster A <sup>1</sup> , Birch KM <sup>5</sup> , Carter G <sup>6</sup> , English C <sup>7</sup> , Farrin A <sup>8</sup> , Holloway I <sup>8</sup> , Lawton R <sup>9</sup> , Patel A <sup>10</sup>
Affiliations:	<sup>1</sup> Academic Unit of Elderly Care and Rehabilitation, University of Leeds, UK
	<sup>2</sup> Centre for Clinical Brain Sciences, The University of Edinburgh, UK
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	<sup>8</sup> Clinical Trials Research Unit, University of Leeds, UK
	9School of Psychology, University of Leeds, UK
	<sup>10</sup> Anita Patel Health Economics Consulting Ltd

**Aim:** Stroke survivors can spend up to 80% of their day in prolonged sedentary behaviour(s) (sitting/lying/reclining). Interventions tailored to the needs of stroke survivors to support an increase in frequency and duration of upright behaviours (standing and walking) are needed. This study aims to understand current behaviour(s) and perceptions of stroke survivors, caregivers and staff, and existing work practices within stroke services.

**Methods:** (1) Non-participant observations in two UK (Scotland, England) stroke services, each including a stroke unit and linked community service (132.5 hours); (2) Fifty-nine semi-structured interviews with staff, stroke survivors and their caregivers to explore capabilities, opportunities and motivations associated with reducing sedentary behaviour (stroke survivors) and supporting stroke survivors to reduce sedentary behaviour (staff and caregivers). Field-note data were thematically analysed and interview data were analysed using the Framework method.

**Findings:** The physical and social environment, perceptions of stroke survivors' physical and psychological capability to increase upright behaviours and be active, and routinized practices enacted by staff, contribute to a consistent pattern of sedentariness in the inpatient setting. This behaviour can become habitual, and is often carried over when stroke survivors leave hospital; however, stroke survivors perceive greater control over their behaviour upon returning home. Most staff, stroke survivor and caregiver interviewees recognised the value of reducing sedentary behaviour after stroke, and certain routine staff activities already promote breaking up sedentary behaviour, for example, fatigue management strategies such as spreading activities across the whole day. However, staff expressed willingness to develop their knowledge of safe, appropriate and more direct













methods to encourage stroke survivors to reduce / break up sedentary behaviour. Interviewees perceived that strategies that can be integrated within the daily lives of stroke survivor and that incorporating meaningful activities will be acceptable and effective.

**Conclusion:** Efforts to reduce sedentary behaviours in stroke survivors are recognised as necessary and potentially beneficial for improving long-term outcomes. Findings from this study are informing a co-production study taking place in two sites (Scotland, England) to develop a tailored sedentary behaviour intervention.

Poster Abstract 10	
Title:	Development of an intervention to reduce sedentary behaviour after stroke: a co-production approach
Authors:	Sarah Morton <sup>1</sup> <b>Other authors:</b> Fitzsimons C <sup>2</sup> , Hall J <sup>3</sup> , Lawton R <sup>4</sup> , English C <sup>5</sup> , Clarke DJ <sup>3</sup> , Birch KM <sup>6</sup> , Carter G <sup>7</sup> , Farrin A <sup>8</sup> , Forster A <sup>3</sup> , Holloway I <sup>8</sup> , Mead G <sup>9</sup> , Patel A <sup>10</sup> , Lawton R <sup>11</sup>
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**Background**: Time spent in sedentary behaviours (sitting / lying / reclining without otherwise being active) in the general population has been associated with reduced physical function, poor mental health and increased cardiovascular risk. Stroke survivors, as a patient population, are known to be highly inactive, and therefore sedentary. Reducing time spent in sedentary behaviours and breaking the pattern of long uninterrupted sedentary events, could have substantial long-term benefit. Intervention strategies to break up and reduce extended periods of sitting and lying are lacking.

**Aims:** Using a collaborative and iterative co-production approach this study looks to develop a robust intervention, suitable for integration into the UK stroke care pathway.

**Methods:** Systematic reviews were undertaken (Oct17 – June18) to update evidence on adults' perceptions and views of sedentary behaviour, effective intervention components and health outcomes. Review findings, together with observational data from inpatient and community stroke services, and interviews with stroke survivors, caregivers and stroke service staff, will be integrated into five co-production workshops running













concurrently in Bradford and Edinburgh (Oct18 – Feb19). Guided by the COM-B model of behaviour change (Capability, Opportunity and Motivation to change Behaviour), stroke survivors, caregivers, and staff will define user needs in relation to reducing sedentary behaviours, and consider appropriate intervention components.

**Findings:** We intend to develop an intervention based on user needs and co-produced by end users, to increase the acceptability and effectiveness of the intervention. The prototype will be tested during a feasibility trial (2019) ahead of a planned 34-site RCT (2020 onwards). The intervention will focus on increasing the frequency and duration of time spent in upright behaviours (standing and walking) to encourage a reduction in sedentary behaviour in a population recognised as having high levels of inactive behaviour in comparison to their healthy age-matched counterparts.

**Conclusion:** This work will generate, using the needs, lived experiences, and expertise of stroke survivors, caregivers and stroke service staff, a co-produced intervention to reduce or break up sedentary behaviours after stroke. A successful intervention has potential to substantially improve long-term functioning, health, and well-being outcomes for stroke survivors.

Poster Abstract 11	
Title:	Greenspace interventions to encourage long-term independence post-stroke: a rapid review
Authors:	Sarah Morton <sup>1</sup>
	Other authors: Mead G <sup>2</sup> , Fitzsimons C <sup>3</sup> , Ward Thompson, C <sup>4</sup> , Hicks K <sup>4</sup>
Affiliations:	<sup>1</sup> Centre for Clinical Brain Sciences, University of Edinburgh, UK
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**Background:** Access to good quality greenspace is highly beneficial for health and wellbeing – both mental and physical. Efforts to increase accessibility for different patient populations (e.g. Type 2 Diabetes, cardiovascular disease, and dementia) are gaining popularity and there is interest in increasing availability, particularly in terms of offering patients an alternative to indoor physical activity and/or rehabilitation. Much work has been done in the context of physical activity and rehabilitation for stroke survivors, however there is less evidence highlighting the potential benefits of access to greenspace following stroke. This work looks to explore this, and to ascertain if there could be benefit in developing a greenspace-based rehabilitation intervention post-stroke.

**Methods:** A rapid review of evidence was undertaken to: understand how greenspace is (variously) defined and establish the parameters of 'access to greenspace' (i.e. does engagement have to be physical, or can viewing greenspace also have an effect?); survey empirical evidence of those health conditions that have benefited from a greenspace intervention, including outcomes; understand the pathways to benefits of accessing greenspace, including relationships to quality and accessibility of greenspace; and identification of other greenspace trials, and a summary of these (including outcomes if available).











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**Findings:** The review found few studies about the benefits of greenspace for stroke survivors, with just one study indicating that access to greenspace could result in improved survival rates following ischemic stroke. Outcomes for other health conditions in the wider population, particularly mental health, appear to be positive and there is much evidence to suggest positive health benefits for a wide range of health conditions. However, delivery method of interventions to encourage engagement with greenspace was identified as a key component of initial and sustained engagement, as was quality of greenspace. Outcome measures appear to reflect short-term effects, and are largely qualitative.

**Conclusion:** This work indicates a lack of evidence exploring how stroke survivors might benefit from greenspace, and therefore there is potential for further work in this area, including developing a greenspace intervention to support rehabilitation post-stroke. Based on studies relating to other health conditions, it seems it would be appropriate to involve users in developing an intervention (co-production).

Poster Abstract 12	
Title:	Understanding Scottish Community Nurses' attitudes and behaviours when working with individuals experiencing mental distress while living with a long- term condition.
Authors:	Julie Churchill and David Banks
Affiliations:	QMU Person-centred Practice Research Division

**Aims:** This specifically included understanding what Scottish Community Nurses would find helpful to increase awareness of, and confidence in, their ability to offer appropriate advice and support to people living with a long term condition and experiencing mental distress

**Methods:** The cardinal method employed was in-depth interviews with 25 Community Nurses employed at different clinical grades, including team leaders, across five Scottish Health Boards, including NHS Lothian. A stakeholders meeting was held with people affiliated to COPE Scotland, who have lived-experience of anxiety and/or depression. Feedback from other key informants, a literature review (funded by QMU P-c P Research Centre) and this event was combined to construct open ended questions. Semi-structured interviews were conducted with participants meeting the above inclusion criteria. Interview data was transcribed and analysed thematically through Framework methodology. Fieldwork was funded by QNIS Scotland.

### **Results:**

<u>Previous career experiences since pre-registration:</u> Participants came from a wide variety of hospital and community based backgrounds. This included experience of working with people experiencing long-term conditions, and mental health issues.

<u>Assessment and building relationships:</u> Divergent practices were revealed based on assumptions regarding job roles, the perceived needs of the person and their competence in working with people with mental health issues.

<u>To intervene or not:</u> Differing levels of awareness around power relationships, specifically in which care setting the interventions were taking place, home or clinic. Interventions more likely to be initiated by nurses with specific education/training. Another influencing factor was working relationships within the Interprofessional team.











<u>Referral:</u> Referral driven by a wide range of practice and procedure based on formal and informal working relationships. Mental Health services clearly valued, but access was an issue. Priorities for some nurses meant Mental Health was not always a high priority issue.

<u>Assets, strengths and possibilities</u>: Practitioners revealed an intriguing range of qualifications and skills revealed by some Practitioners. A clear appetite expressed by some nurses to consolidate this work through further education and experience. There was evidence of innovation in terms of service development, extension of role, advancing practice and advanced practice. These were local initiatives.

**Conclusions:** The analysis offers new understandings into how this key group of professionals provide interventions for people experiencing mental distress whilst living with long term conditions. The findings to some degree challenge assumptions by Health Education England (HEE) about the characteristics of Practice Nursing in Scotland. Finally, innovatory work by individual nurses could be challenged by competing pressures arising from the new GMC Contract.

Poster Abstract 13	
Title:	Investigation of Exocrine Pancreatic Insufficiency Following Surgery for Oesophagogastric Cancer
Authors:	Waheed S, Roy C, Couper GW, Lamb PJ, Paisley AM, Skipworth RJE, Deans DAC
Affiliations:	NHS Lothian, University of Edinburgh

**Background:** Curative treatment for oesophagogastric cancer often involves surgical resection. Studies have suggested that exocrine pancreatic insufficiency (EPI) may occur following oesophagogastric surgery and may account for some of the unpleasant abdominal symptoms commonly experienced by these patients. The aim of this study was to investigate EPI post-surgery and examine the effects of pancreatic exocrine replacement (PERT) for these patients.

**Methods:** Twenty-four patients were recruited into the study. Ten patients underwent gastrectomy and 14 underwent oesophagectomy. Seven patients were reviewed before and after surgery and 17 patients were seen after surgery only. A novel questionnaire was developed to investigate symptoms of EPI (eg diarrhoea, abdominal cramps). All patients completed the questionnaire to determine EPI symptoms, were weighed and tested for faecal elastase-1. Patients with low faecal elastase-1 level (< 450  $\mu$ g/g) were commenced on PERT (Creon) and underwent repeat questionnaire testing following treatment.

**Results:** Ten patients (42%) had faecal elastase < 450  $\mu$ g/g after surgery and this was associated with higher symptom scores [average 4.8 vs 3.1 (range 0-7), p = 0.043; Mann Whitney U Test]. Eight patients were trialled on Creon, and all reported improvement in their symptomatic scores [mean reduction 2.875 (range 1-5 symptoms) p = 0.011; Wilcoxon Signed-Rank Test].

**Conclusions:** EPI is common following oesophagogastric cancer surgery. PERT should be offered to all patients with symptoms consistent with EPI and low faecal elastase-1 values (in our study <450  $\mu$ g/g).











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Poster Abstract 14		
Title:	Lessons learned: evaluation of a centralised system of safety blood monitoring within a multicentre randomised placebo-controlled clinical trial	
Authors:	Holly Ennis and Catriona Keerie	
<b>Affiliations:</b>	Edinburgh Clinical Trials Unit, Usher Institute of Population Health Sciences and Informatics, University of Edinburgh	

**Aims:** Within placebo-controlled drug trial designs, concealing treatment allocation adequately while ensuring the robust collection and interpretation of blood safety data can present significant methodological challenges. This evaluation assesses the use of a centralised safety blood monitoring system employed within the TOPPIC trial, a randomised, placebo-controlled, two-arm parallel group trial assessing whether mercaptopurine (MP) prevented or delayed recurrence of Crohn's disease following surgical resection.

**Methods:** Treatment with MP causes bone marrow suppression leading to leukopenia and thrombocytopenia and, less commonly, to anaemia. Consistent with clinical practice, all randomised participants in both MP and placebo arms underwent regular full blood count monitoring. A centralised blood monitoring system was implemented whereby blood samples were collected and processed at participating sites, with results transferred to the central trial office by independent staff members for entry into a web-based electronic data capture (EDC) system. Blood values were reviewed by a blinded team of clinical assessors, with queries and decisions fed back to site via the EDC system.

**Results:** 240 participants were recruited to the TOPPIC Trial and 4,994 (67.1%) of the total projected number of 7,440 safety blood tests were collected during the trial. Of the 4,994 collected bloods, 4,396 (88.0%) were collected within the target window with a median number of days either side of the target date of 0 (see Table 1). Compliance within the target window for bloods taken at GP visits was higher at 3,089 (90.9%) than those taken at scheduled study visits (81.8%).

A total of 5,088 (15.9%) sets of blood results resulted in abnormal value alerts with a median review time by clinician assessors of 1 day. 809 abnormal value alerts resulted in recommended actions for site teams, with 717 of these (88.6%) documented within the EDC system as actioned at site.

**Conclusions:** The TOPPIC Trial demonstrated that a centralised masked system of safety blood monitoring can be both feasible and efficient within a multi-site trial. The TOPPIC system was considered worthwhile because it reduced the risk of unblinding from routine blood results. The anticipated volume of messages generated should be considered when developing future systems.

ISRCTN89489788, EudraCT 2006-005800-15. Registered 18 October 2006.

### Table 1. Blood test compliance - timings

	Early	Late	On time	Total
GP visit	44 (1.3%)	264 (7.8%)	3,089 (90.9%)	3,397
Scheduled visit	74 (4.6%)	216 (13.5%)	1,307 (81.8%)	1,597
Total	118 (2.4%)	480 (9.6%)	4,396 (88.0%)	4,994











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Poster Abstract 15	
Title:	A qualitative audit of The Heart Manual: Patient reported outcomes, in relation to current cardiac rehabilitation guidelines.
Authors:	Hannah Ranaldi
Affiliations:	NHS Lothian

**Aims:** Patients are offered a range of innovative cardiac rehabilitation programmes after experiencing a cardiac event such as myocardial infarction and/or revascularisation procedure. These programmes are regularly informed by evidence-based guidelines, including those from the Scottish Intercollegiate Guideline Network, the British Association for Cardiac Prevention and Rehabilitation, the National Institute for Health Care and Excellence and the European Society of Cardiology. Yet little is known about which aspects of these guidelines patients find have the greatest impact on their recovery and proves most beneficial. The aim of this audit was to qualitatively examine patient reported outcomes of the Heart Manual (HM) programmes in relation to the current guidelines.

**Methods:** Patient feedback questionnaires that had been returned to the department between November 2011 and January 2018 were included for analysis. Thematic analysis was guided by the framework approach (1). Initially the data was coded deductively using structured topic guides, comprised of the key components of cardiac rehabilitation, to identify patterns within the data and capturing any additional themes which emerged. Secondary analysis looked at the data inductively to allow patient reported subthemes to emerge.

**Results**: Overall, it was evident that patient's felt their recovery benefited greatest from a comprehensive and holistic approach to CR. Initial themes which emerged included: 1. Health behaviour change and modifiable risk reduction; 2. Psychosocial support; (3) Education; 4. Social support; 5. Medical risk management; 6. Vocational rehabilitation; and 7. Long-term strategies and maintenance. As singular components, 1 and 2 were reported as having the greatest impact on patients' daily lives. Subthemes relating to 1 highlighted: guidance, engagement, awareness, consequences, no change and motivation. For 2, patient subthemes demonstrated the impact of: stress management, pacing, relaxation, mental health and self-perception. Less frequently referred to was 5, 6 and 7. Additional themes highlighted the impact of the HM programme.

**Conclusion:** This audit appears to be the first to explore patient reported outcomes of a facilitated, home based cardiac rehabilitation programme in relation to current guidelines. These findings provide substantial, illustrated and previously unexplored accounts of patients' experience and highlight the profound impact these programmes can have for cardiac rehabilitation and secondary prevention. These findings further evidence the HM as a validated programme which meets current local, national and European level guidance. Utilising this innovate approach for auditing the HM programme has not only enabled better understanding of its impact, but also supports NHS Scotland's priorities for heart disease management and rehabilitation. In our presentation we will elucidate the findings, as published in the BMJ Open (doi:10.1136/bmjopen-2018-024499).













Poster Abstract 16	
Title:	The role of the Scottish Human Papillomavirus (HPV) Archive in National Surveillance of HPV vaccination
Authors:	Elia Alcaniz Boada, Ramya Bhatia, Heather Cubie and Kate Cuschieri
Affiliations:	University of Edinburgh

**Aim:** To provide a biobanking resource to support national HPV vaccination surveillance and associated research in Scotland.

#### Methods:

- National surveillance and vaccination programmes

The HPV immunisation programme started in 2008 targeted at girls aged 12-13 years, together with a catchup campaign for older girls (13-17), which ran over three years. With cervical screening being offered to all eligible women aged 20 to 60 every three years (which changed to 25-65 in 2016), the first vaccinated girls started entering screening in 2011, providing an optimal scenario to assess the impact of bivalent HPV vaccine on viral and disease outcomes.

- Archive constitution and governance

The Scottish HPV Archive<sup>1</sup> is a "collection of collections" and includes samples collected from the National Surveillance programme and other research and clinical projects. The archive is associated with Research Tissue Bank status and comes under the wider auspice of the Lothian NRS BioResource<sup>2</sup>. Applications for access to samples are adjudicated by a steering committee. Samples can be linked to several datasets, ensuring that the Scottish HPV Archive has cytology, histology and colposcopy data as well as vaccination status and HPV results on a majority of samples.

**Results:** Key specific contributions by the archive biobank and team to support HPV surveillance have shown HPV vaccine impact on various outcomes, leading to 14 peer-reviewed publications. Evidence shows a 90% reduction of vaccine type HPV infection (HPV 16 and 18) in women attending for first cervical smear<sup>3,4,</sup> Moreover, there is solid evidence of cross-protection for other types (HPV 31, 33 and 45), herd immunity in unvaccinated women and a significant reduction in histological abnormalities in vaccinated cohorts<sup>5,6.</sup> These outputs have attracted significant positive coverage at scientific meetings and in the media<sup>7.</sup>

**Conclusions:** The Scottish HPV Archive is an invaluable resource which supports National HPV vaccination surveillance and associated research. High efficacy of the vaccine has been demonstrated through the monitoring of HPV infection, providing robust evidence for the effectiveness of 10 years of the Scottish programme.

<sup>7</sup> https://www.bbc.co.uk/news/uk-scotland-39493859







<sup>&</sup>lt;sup>1</sup>www.ed.ac.uk/pathology/research/scottish-hpv-archive

<sup>&</sup>lt;sup>2</sup> https://www.accord.scot/tissue

<sup>&</sup>lt;sup>3</sup> Kavanagh K, Pollock KG, Potts A, Love J, Cuschieri K, Cubie H, Robertson C, Donaghy M. Introduction and sustained high coverage of the HPV bivalent vaccine leads to a reduction in prevalence of HPV 16/18 and closely related HPV types. Br J Cancer. 2014 May 27; 110 (11):2804-11.

<sup>&</sup>lt;sup>4</sup> Bhatia R, Kavanagh K, Cubie HA, Serrano I, Wennington H, Hopkins M, Pan J, Pollock KG, Palmer TJ, Cuschieri K. Use of HPV testing for cervical screening in vaccinated women—Insights from the SHEVa (Scottish HPV Prevalence in Vaccinated Women) study. Int J Cancer. 2016 Jun 15; 138(12):2922-31.

<sup>&</sup>lt;sup>5</sup> Kavanagh K, Pollock KG, Cuschieri K, Palmer T, Cameron RL, Watt C, Bhatia R, Moore Cm Cubie H, Cruickshank M, Robertson C. Changes in the prevalence of human papillomavirus following a national bivalent human papillomavirus vaccination programme in Scotland: a 7-year cross-sectional study. Lancet Infect Dis. 2017 Dec;17(12):1293-1302.

<sup>&</sup>lt;sup>6</sup> Pollock KG, Kavanagh K, Potts A, Love J, Cuschieri K, Cubie H, Robertson C, Cruickshank M, Palmer TJ, HPV bivalent vaccine in Scotland. Br J Cancer. 2014 Oct 28; 111(9): 1824-30.





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Poster Abstract 17		
Title:	Feasibility study to demonstrate rapid cartridge-based identification of HPV in oropharyngeal cancer samples	
Authors:	D. Guerendiain <sup>a</sup> , S. Malini <sup>b</sup> , A. Donovan <sup>b</sup> , B. Conn <sup>c</sup> , E. Kelly <sup>d</sup> , S. Coughlan <sup>d</sup> , K.Cuschieri <sup>a</sup>	
Affiliations:	<sup>a</sup> Scottish HPV Reference Lab, Royal Infirmary of Edinburgh, UK.	
	<sup>b</sup> Cepheid, Sunnyvale, USA	
	<sup>c</sup> Department of Pathology, Royal Infirmary of Edinburgh, UK	
	<sup>d</sup> University College Dublin, National Virus Reference Laboratory	

**Aims:** Incidence of human Papillomavirus (HPV) related oropharyngeal cancer (OPC) has risen dramatically over the last 2-3 decades. Furthermore, there is an increasing demand for HPV annotation of OPC using formalin fixed paraffin embedded (FFPE) biopsy material, as HPV-related OPCs have a better prognosis than HPV-negative OPCs. The objective of this study was to determine the feasibility of a rapid molecular test for the rapid determination of the HPV status of oropharyngeal cancers.

**Methods:** In this pilot study, a total of 54 FFPE 10  $\mu$ m sections derived from OPC diagnosed between 2014 – 2015 were assessed. Each section was processed using the Xpert FFPE Lysis Kit protocol prior to the HPV detection by the Xpert HPV assay. Samples were previously analysed for HPV using a Luminex DNA detection assay (OptiPlex, DiaMex, Germany) and by p16 immunohistochemistry (IHC). Between-assay agreement was assessed: Positive, negative and overall percent agreement (PPA, NPA and OPA) and McNemar's were calculated.

Furthermore, an inter-lab comparison of the assay on a 25 FFPE panel of clinical and simulated material was tested, in duplicate, across the Scottish HPV Reference Laboratory, Edinburgh and the University College Dublin (UCD), National Virus Reference Lab.

**Results:** The process from FFPE-section to result using the Xpert system was less than 2 hours, with little hands-on time. Four samples had invalid results. Comparison of the technically valid results showed an overall predictive agreement of Xpert vs p16 and Xpert vs Luminex assay of 88% and 87% respectively.

The inter-lab comparison obtained an agreement of 92% and a Kappa of 0.8375. Discrepant results were observed in 2/50 samples; notably both discrepant cases were associated with only one of the two replicates tested. The semi quantitative output of the assay also indicated that a low-viral load was associated with the discrepant.

**Conclusions:** It is technically feasible to detect high risk HPV in OPC material using the Xpert HPV assay and the associated extraction process. Moreover, inter-lab agreement was high indicating the technical robustness of this approach. The observed high agreement between the Xpert vs more established assays (p16 and OptiPlex) is encouraging and warrants a further assessment of the assay in a larger series of OPC where results will be linked to clinical outcomes.













Poster Abstract 18	
Title:	Baseline audit of alternative and augmentative communication aid use by people with motor neurone disease in Scotland
Authors:	Elizabeth Elliott <sup>2,3,4</sup> , Judith Newton <sup>1,2,3,4</sup> , Phillipa Rewaj <sup>2,3</sup> , Jenna M Gregory <sup>2,8</sup> , Lynda Tomarelli <sup>2,3</sup> , Shuna Colville <sup>1,2,3,4</sup> , Siddharthan Chandran <sup>1,2,3,4,8</sup> , Suvankar Pal <sup>1,2,3,4,7,8</sup> on behalf of the CARE-MND Consortium <sup>1</sup>
Affiliations:	<sup>1</sup> Clinical Audit Research and Evaluation for Motor Neurone Disease, Scotland UK, <sup>2</sup> Euan MacDonald Centre for Motor Neurone Disease Research, University of Edinburgh, Anne Rowling Regenerative Neurology Clinic, Royal Infirmary, Edinburgh <sup>3</sup> , NHS Lothian <sup>4</sup> , NHS Greater Glasgow and Clyde <sup>5</sup> , NHS Tayside <sup>6</sup> , NHS Forth Valley <sup>7</sup> , Centre for Clinical Brain Sciences, University of Edinburgh <sup>8</sup>

**Aims:** People with moto neurone disease (pwMND) experience speech dysfuction which can be supported by alternative and augmentative communication (AAC). We conducted a baseline audit of communication support for pwMND in Scotland against NICE guidance to inform and improve future service provision.

**Methods:** A cross sectional population based audit was undertaken. Anonymised demographic and clinical phenotypic data for all pwMND in Scotland were extracted from the Care Audit Research Evaluation of MND (CAREOMND) platform, the National MND Register for Scotland. Additional information for AAC provision was provided by the third sector charitable organisation MND Scotland (MNDS).

**Results:** 371 pwMND were included in the analysis, 43% of all pwMND were recorded as having impaired speech (recent ALSFRS-R score assessment  $\leq$ 3) and 69% of all pwMND had been referred to speech and language therapy (SALT) services although there was significant variation in referral time. 36% of all pwMND were using a range of mainly high technology AAC to support either speech and/or limb dysfunction. The most frequently AAC used included: iPade, one tracking technology and the Lighturiter<sup>TM</sup>

dysfunction. The most frequently AAC used included; iPads, eye tracking technology and the Lightwriter<sup>™</sup> speech generating device.

**Conclusions:** Over a third of all pwMND across a range of MND disease subtypes were using AAC equipment to support both speech and limb dysfunction. Early access to SALT services is advised to enable prospective and personalised decision making. Further qualitative research is required to understand the preferences and impact of AAC from the perspectives of the user and their communication partners.











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Poster Abstract 19	
Title:	Embedding a Health Promoting culture in NHS Lothian: A pilot project within Primary Care Pharmacy
Authors:	Alison Eadie
Affiliations:	Health Promotion Specialist – NHS Lothian

**Aims:** The overall objective for the pilot project was to develop a means of supporting NHS Lothian practitioners to embed health promotion in their daily patient care, ensuring that 'every health care contact is a health improvement opportunity'. Phase 1 of the pilot aimed to increase the understanding of the training needs of Primary Care Pharmacists in relation to health promotion. This understanding was used throughout phase 2 to design and facilitate training that aimed support Primary Care Pharmacists to confidently embed health promotion approaches into their daily practice. Phase 3 evaluated the training, specifically aiming to assess the impact on patient outcomes and the daily practice of staff.

**Methods:** Focus groups were carried out with a range of professionals from NHS Lothian's Primary Care Pharmacy team at phase 1 (start of project) and phase 3 (3 month follow up) to fulfil their respective aims. Phase 2 of the pilot delivered a 10 hour training session that focused on supporting participants to develop knowledge of health promotion approaches, health inequalities and to embed health promoting conversations in their daily practice with patients.

### **Results:**

*Phase 1*: Two focus groups (N = 14) were conducted, and following analysis training needs were identified and grouped into three main themes: (1) knowledge and awareness of health promotion, (2) overview of wider determinants of health and main health behaviour topics / risk factors, and (3) how to raise health promotion related issues and communicate health promotion messages. Staff also indentified additional support they would need to embed and record health promoting conversations with their patients, and described barriers they had previously encountered or anticipated to working this way.

*Phase 2*: Training to address these needs was developed by the Health Promotion Service and was delivered to six members of the Primary Care Pharmacy team. Training was spread over 1.5 days and focused on addressing the needs identified in phase 1 with a specific emphasis on equipping participants to implement what they had learnt in practice.

*Phase 3*: Evaluation completed immediately following the training were overwhelmingly positive: participants indicated that all seven of the learning outcomes had been completely met and additionally that they believed the training would be beneficial to their work. Results from the 3 month follow up focus group were similarly extremely positive: participants described how they felt confident at recognising opportunities for health promotion and to subsequently have supportive conversations that addressed the holistic determinants of health into their daily interactions with their patients.

**Conclusions:** It is important to recognise the varying levels of awareness of health promotion topics, skills and approaches in the wider NHS workforce and develop tailored training to increase knowledge and confidence in applying this culture in practice. Training such as this will allow practitioners to confidently embed approaches focuses on early intervention, prevention and health promotion into their daily interactions with patients, contributing to a NHS culture that holistically supports all aspects of individual health and wellbeing.











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Poster Abstract 20	
Title:	Antiviral innate immune response in non-myeloid cells is augmented by chloride ions via an increase in intracellular hypochlorous acid levels
Authors:	Sandeep Ramalingam <sup>1,2</sup> , Baiyi Cai <sup>2</sup> , Junsheng Wong <sup>2</sup> , Matthew Twomey <sup>2</sup> , Rui Chen <sup>2</sup> , Rebecca M. Fu <sup>2</sup> , Toby Boote <sup>2</sup> , Hugh McCaughan <sup>1,2</sup> , McNab M <sup>2</sup> , Samantha J. Griffiths <sup>2</sup> & Jürgen G. Haas <sup>1,2</sup>
Affiliations:	<sup>1</sup> Department of Laboratory Medicine, NHS Lothian, <sup>2</sup> Division of Infection and Pathway Medicine, University of Edinburgh.

**Aims:** Hypertonic saline is often used to treat sinusitis, bronchiolitis and sore throat. The clinical benefit is usually attributed to its mucolytic effect. Reports from the 1960's suggest an antiviral effect. Phagocytes destroy ingested microbes within phagolysosomes by producing hypochlorous acid (HOCl) from chloride ions (Cl-) and hydrogen peroxide using the enzyme myeloperoxidase. HOCl, the active ingredient in bleach, has antibacterial/antiviral properties. As myeloperoxidase is needed for HOCl production, non-myeloid cells are considered incapable of producing HOCl. We investigated whether viral replication was inhibited in the presence of Sodium Chloride (NaCl). Here, we show that epithelial, fibroblast and hepatic cells have enhanced antiviral activity in the presence of increasing concentrations of NaCl.

**Methods:** We investigated whether viral replication was inhibited in the presence of NaCl with enhanced green fluorescence protein (eGFP) labelled herpes simplex virus type 1 (HSV-1) grown in HeLa cells (epithelial). On identifying viral inhibition, we attempted to understand the mechanism behind it and whether this effect was seen with other DNA/RNA viruses such as, eGFP murine herpesvirus 68 (MHV-68) (3T3 fibroblast cells), eGFP respiratory syncytial virus (RSV) (HeLa cells), influenza A virus (A549 cells), eGFP human coronavirus 229E (HCoV-229E) (HUH-7 hepatoma cells) and eGFP coxsackievirus B3 (CV-B3) (HUH-7.5 cells). Replication was measured by flourescence for eGFP viruses. Quantitative RTPCR was used for Influenza A virus.

**Results:** Replication of enveloped/non-enveloped, DNA (HSV-1, MHV 68) and RNA (RSV, influenza A virus, HCoV 229E, CV-B3) viruses are inhibited in a dose-dependent manner. Whilst treatment with sodium channel inhibitors did not prevent NaCl-mediated virus inhibition, a chloride channel inhibitor reversed inhibition by NaCl, suggesting intracellular chloride is required for antiviral activity. Inhibition is also reversed in the presence of 4-aminobenzoic hydrazide, a myeloperoxidase inhibitor, suggesting epithelial cells have a peroxidase to convert Cl<sup>-</sup> to HOCl. A significant increase in intracellular HOCl production is seen early in infection.

**Conclusions:** These data suggest that non-myeloid cells possess an innate antiviral mechanism dependent on the availability of chloride ion to produce HOCl. Antiviral activity against a broad range of viral infections can hence be augmented by increasing availability of NaCl. This hypothesis forms the basis of ELVIS, a pilot RCT of hypertonic saline nasal irrigation and gargling in adults with the common cold (abstract submitted) and ELVIS Kids (a large RCT of salt water nose drops in children with a common cold).













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Poster Abstract 21	
Title:	Targeting Rehabilitation to Improve Outcomes following total knee arthroplasty (TRIO): a randomised controlled trial of physiotherapy intervention
Authors:	<b>David Hamilton</b> <sup>1</sup> David Beard, Karen Barker, Gary MacFarlane, Andrew Stoddart, Gordon Murray, Hamish Simpson
Affiliations:	<sup>1</sup> University of Edinburgh

**Aims:** There is a lack of evidence as to how to deliver rehabilitation following TKA. Previous work has suggested that physiotherapy for all patients is not effective at improving one-year post-surgical outcomes. The aim of this study was to target physiotherapy to those at risk of poor outcome following TKA, and to determine if a therapist-led intervention offered superior results compared to a home-exercise based protocol in this 'at risk' group.

**Methods:** The Targeted Rehabilitation to Improve Outcomes (TRIO) study was a prospective randomised controlled trial led and run by Edinburgh, recruited across 13 UK centres. Patients were identified as 'potential poor outcome' based on an Oxford Knee Score (OKS) classification at 6-weeks post-surgery and randomised to either therapist-led or home-exercise based protocols. Patients were reviewed by a physiotherapist and commenced 18-exercise sessions over 6-weeks. The therapist-led group undertook a progressive functional protocol (modified weekly in 1-1 contact sessions) in contrast to a 'static home-exercise' regime. Evaluation took place following rehabilitation intervention, then at 6-months and 1-year post-surgery. Primary outcome was comparative group OKS at 1-year. Secondary outcomes included, 'worst' and 'average' pain scores, OXS and EQ-5D, and satisfaction questionnaire. Health economic (cost-utility) analysis was undertaken up to 1-year post-surgery. Incremental cost per Quality Adjusted Life Years (QALYs) were calculated from intervention costs, patient reported primary and secondary care usage, and EQ-5D data.

**Results:** 4264 patients were screened, 1296 were eligible, 334 patients were randomised, 8 were lost to followup, therapy compliance was >85%. Clinically meaningful improvement in OKS (between baseline and 1-year) was seen in both arms (p<0.001). Between group difference in 1-year OKS was 1.91 (95%CI, -0.17-3.99) points favouring the therapist-led arm (p=0.07). Incorporating all time point data, between group difference in OKS was 2.25 points (95%CI, 0.61-3.90, p=0.008). Small, non-significant reductions (<5%) in both worst and average pain scores were observed favouring the therapist-led group. Enhanced satisfaction with pain relief (OR 1.65, p<0.02), ability to perform daily functional tasks (OR 1.66, p<0.02), and perform heavy functional tasks (OR 1.6, p=0.04) was reported in the therapist-led group. There was a small non-significant difference of 0.02 points (95%CI -0.02–0.06) between groups in EQ-5D, resulting in a £12,125 cost per QALY of delivering the therapist-led intervention with a 57% chance of being cost-effective at a £20,000 policy threshold.

**Conclusions:** TRIO is the largest European randomised trial of physiotherapy following TKA, and the first to target rehabilitation to patients at risk of poor outcomes. Both therapist-led and home-exercise based rehabilitation groups made clinically meaningful improvements in outcome by 1-year. We observed a modest difference in OKS in favour of therapist-led rehabilitation compared to the home-exercises which was not statistically significant. The relatively tight confidence intervals suggests that any difference which might exist is too small to be clinically relevant. While cost-per-QALY estimates were below policy threshold, this result is uncertain and insufficient to make accept-decline recommendations. Patient satisfaction with outcome was however higher in those that received greater physiotherapist contact, and this may in itself justify the additional rehabilitation targeted to patients at risk of poor outcomes.











Academic and Clinical Central Office for Research and Development

Poster Abstract 22	
Title:	Alcohol Related Brain Damage: Does an Increase in Executive Function during Abstinence-based Treatment Predict Health Outcomes at Follow-up?
Authors:	Annette Morrison
Affiliations:	NHS Lothian

**Aims**: Reducing the national indicator of 'alcohol related admissions to hospital' is one of Scotland's key health priorities (Scottish Government, 2009). However, alcohol-related hospital admissions have increased by nearly 2% from 2015/16 to 2016/17 in Scotland. Patients with Alcohol Related Brian Damage (ARBD) show impaired Executive Functioning (EF) i.e. higher-level thinking (Svanberg and Evans, 2013). A recent 'bi-directional' model suggests EF facilitates health behaviour, while health behaviour facilitates EF (Allan et al., 2016). Aims are to test the bi-directional model in the ARBD population - investigating if an increase in health behaviour (abstinence) improves EF, and if an increase in EF predicts positive health outcome (reducing admissions to hospital).

**Methods**: A within-subjects, repeated-measures and correlational design was used. Patients were recruited through attendance at 12 week NHS Lothian and 3<sup>rd</sup> Sector Partnership ARBD unit. Frontal Assessment Battery (Appollonio et al., 2005) was used to measure EF (at beginning and end of stay), while A+E attendance and Inpatient admissions were recorded pre and post treatment as measure of health outcome.

**Results**: Paired-samples t-tests found patients (n=46) improved their EF significantly through abstinence programme (d= .499, p<.01), and attended A+E and hospital significantly less at 3, 6 and 12 months follow-up (p<.01). Correlations showed EF improvement was not significantly associated with the improved health outcomes (p>.05). Effect sizes did not indicate EF to be a better predictor than general cognitive ability at all time points.

**Conclusions**: The MDT service is effective in reducing patient stays in hospital, attendances at A+E and in significantly increasing patient cognitive ability. The novel bi-directional model (Allan et al., 2016) was not supported. Likely explanations include an underpowered correlation analysis.











Academic and Clinical Central Office for Research and Development

Poster Abstract 24	
Title:	Immunoglobulin Gene Homology Validation: Is <i>IGHV</i> Sequencing Still Relevant?
Authors:	Laura Benson
Affiliations:	HMDS/Molecular Pathology, Western General Hospital, Edinburgh

**Aims:** Determination of the mutation status of the immunoglobulin heavy-chain variable gene (*IGHV*) is a highly prognostic indicator in patients with chronic lymphocytic leukaemia (CLL) as it enables CLL to be classified as unmutated (U-CLL) or mutated (M-CLL). U-CLL is associated with: a shorter time to disease progression, a shorter time to first treatment and a shorter overall survival in patients with CLL. M-CLL is associated with a more favourable prognosis. *IGHV* rearrangements can belong to a major stereotyped subset, which also provide prognostic information, independent of mutation status. A Sanger sequencing-based assay was developed and validated within the Haematology Malignancy Diagnostic Service (HMDS) in Edinburgh for service implementation. A clinical audit of the samples used to validate the assay was performed to establish the utility of the assay in the era of modern therapies that target the tumour protein p53 gene (*TP53*).

**Methods:** A Sanger sequencing-based assay was developed using 2 multiplex polymerase chain reaction (PCR) primer sets: one targeting the *IGHV* Leader strand and the other targeting frame-work region 1 of *IGHV*. Both primer sets were paired with a primer targeting the joining region (*IGHJ*) of the immunoglobulin heavy-chain gene. BigDye Terminator sequencing was performed on 27 samples. Detected sequences were aligned to the closest germline counterpart using the online International ImMunoGeneTics database (IMGT/V-QUEST) to determine mutation status. Assessment of stereotype subset was performed using the ARResT/AssignSubets online alignment tool.

**Results:** Sequencing data were obtained for 26 of 27 patients analysed. Approximately 42% of patients were classified as U-CLL ( $\geq$ 98% homology to germline sequence) with 50% classified as M-CLL (<97% homology to germline sequence). The remaining 8% (2 patients) demonstrated homology of 97-97.99% to germline sequence and were classified as "equivocal". Of the 26 cases, 3 (11.5%) belonged to a major stereotyped subset. In one of these three cases, the patient was classified as M-CLL (associated with a more favourable prognosis). However, the stereotype subset indicated a less favourable prognosis, suggesting that the patient should be treated more aggressively than the mutation status would imply.

A clinical audit of the relevant patient details was performed. Overall, 10 patients (6 U-CLL;3 M-CLL;1 equivocal) were treated with the Bruton's tyrosine kinase-inhibitor ibrutininb, 2 patients (1 U-CLL;1 equivocal) were treated with the phosphoinositide-3 kinase (PI3K) delta inhibitor idelalisib, and 11 patients (4 U-CLL;7 M-CLL) received conventional therapies. The *IGHV* mutation status was a prognostically important biomarker for the group of CLL patients. Furthermore, the patient classified as M-CLL with a poor prognostic stereotype subset required early treatment indicative of a more aggressive disease.

**Conclusions:** Sanger sequencing was successfully validated for the determination of IGHV mutation status in patients with CLL and has been implemented within NHS Lothian. Sequencing of *IGHV* along with assessment of stereotype subset is a reliable method to aid with treatment choices for patients with CLL. International guidelines (European Research Initiative on CLL) provide resources for classification of mutation status with reference to difficult cases such as those with double rearrangement.











Academic and Clinical Central Office for Research and Development

Poster Abstract 25	
Title:	How often do NHS Lothian podiatrists discuss Charcot foot?
Authors:	Benjamin Bullen, Matthew Young, Carla McArdle, Mairghread Ellis
Affiliations:	Queen Margaret University, NHS Lothian

**Aims:** In 2016-17, all podiatrists employed by or holding honorary contracts with NHS Lothian were invited to participate in a modified Delphi approach to develop consensus concerning 'At-risk' Charcot foot patient education. Over two rounds participants agreed, contrary to current national guidance, Charcot foot patient education should be delivered to all individuals with diabetic peripheral neuropathy (DPN) as well as those with active or previous disease. This research subsequently sought to benchmark and compare frequency of discussion of a variety of topics relevant to diabetes foot disease, including Charcot foot, between all 'At-risk' individuals with DPN and those 'In Remission' from Charcot foot.

**Methods:** Self-reported frequency of discussion data was captured with an ordinal five-point Likert scale, rated as Never (1); Rarely (2); Sometimes (3); Often (4) or Always (5). Topics investigated for both 'At-risk' and 'In Remission' groups included diabetes foot ulceration (DFU) and amputation risk, footwear and insoles and signs of infection and Charcot foot. Median response and interquartile range (IQR) were described and compared between groups.

**Results:** While 14 participants completed an 'At-risk' component of the *Charcot Foot Patient Education Questionnaire*, a subset of six also responded to questions concerning individuals 'In Remission' from Charcot foot. Median values and IQR for discussion of DFU- and LEA-risk were 5 (IQR: 1) and 3 (IQR: 1.25) respectively among 'At-risk' groups and 5 (IQR: 0.25) and 3 (IQR: 2) respectively among 'In Remission' groups. For discussion of footwear and insoles, the median response was 4 (IQR: 1) for 'At-risk' and 5 (IQR: 1) for 'In Remission' groups, however, these values were reversed for discussion of signs of infection. The greatest between-group discrepancy was found for discussion of Charcot foot, with median responses and IQR found to be 3 (IQR: 2) and 5 (IQR: 0.25) for 'At-risk' and 'In Remission' groups, respectively.

**Conclusions:** This discrepancy has potential implications for future Charcot foot educational strategies, audit and research. It is proposed 'Always' should be the benchmark for frequency of Charcot foot education, not just for those 'In Remission' but also 'At-risk' individuals with DPN. The Comparing Charcot foot Health literacy between 'At-risk' and 'In Remission' groups (CCHAIR) Study will describe current impact on NHS Lothian service users.











Academic and Clinical Central Office for Research and Development

Poster Abstract 26	
Title:	<b>Generation Scotland - Using Electronic Health Records for Research</b>
Authors:	Archie Campbell, Rachel Edwards, David Porteous
Affiliations:	University of Edinburgh

**Aims:** Generation Scotland: Scottish Family Health Study (GS:SFHS) is a family-based genetic epidemiology study of ~24,000 volunteers from ~7000 families recruited across Scotland between 2006 and 2011 with the capacity for follow-up through record linkage and re-contact. Broad consent was obtained for linkage to "medical records" for 98% of the cohort. This created a resource for investigation of the genetics of common conditions, available to researcher in Scotland, the UK and worldwide.

**Methods:** Participants completed a demographic, health and lifestyle questionnaire, provided biological samples, and underwent detailed clinical assessment. The samples, phenotype and genotype data collected form a resource with broad consent for research on the genetics of health, disease and conditions of current and projected public health importance. This has become a longitudinal dataset by linkage to routine NHS hospital, maternity, lab tests, prescribing and dental records, using the Scottish Community Health Index (CHI). Mortality data has been obtained from the General Register of Scotland. We plan to use the GoSHARE register to obtain new research samples from routine NHS tests.

**Results:** Researchers can now use the linked datasets to find prevalent and incident disease cases, and healthy controls, to test research hypotheses on a stratified population. They can also do targeted recruitment of participants to new studies, including recall by genotype, utilising the NHS CHI register for current contact details. We have now established and validated EHR linkage, overcoming technical and governance issues in the process. Using consented data avoids some limitations of safe havens for analysis.

Genome-wide association studies (GWAS) have been done on a wide range of quantitative traits and biomarker measurements. Generation Scotland is a contributor to major international consortia, with collaborators from many institutions from the UK and worldwide, both academic and commercial. GS has also collaborated with Dementia Platforms UK and Health Data Research (HDR) UK to make the resources more widely known. There have been over 300 research collaborations, and GS data has contributed to 200 published papers, with more in the pipeline.

**Conclusions:** Generation Scotland have thoroughly tested the linkage process and are now extending it to include primary care data (GP records) and scanned images (PACS) this year, with plans to collect more samples and data. The GS resources are available to academic and commercial researchers through a managed access process (<u>www.generationscotland.org</u>). Participants can be invited to take part in new studies, targeted by phenotype, genotype, or presence or absence of a condition in their medical records.











Academic and Clinical Central Office for Research and Development

Poster Abstract 27	
Title:	Activity Tracker Use in Community Stroke Rehabilitation
Authors:	Cathy Cheyne, Gill Murray, Leigh Fawcett, Physiotherapists
Affiliations:	NHS Lothian

**Aims:** Patients attending Edinburgh Community Stroke Service (ECSS) frequently report low activity levels. This project aimed to increase physical activity in ambulant clients following a stroke. We sought to provide clients receiving post stroke physiotherapy with concurrent use of free activity tracker technology and promote increased awareness of activity levels. The longer term aim was to encourage sustained self-management of physical activity following discharge.

**Method:** Patients attending ECSS between November 2016 and May 2017 who were independently mobile, with or without a walking aid and who identified increasing physical activity as a rehabilitation goal were invited to participate. Physiotherapists established patient's baseline physical activity level on initial assessment or with the use of a physical activity diary. Patients were then provided with a Garmin Vivofit or Fitbit Flex Activity Tracker to wear daily. ECSS Support Workers were trained to support a patient in the use of the tracker and retrieve the weekly step count data. This was synced with a secure ECSS iPad when patients attended the service for their rehabilitation. Physiotherapists reviewed progress with the patients at each attendance and activity targets were set for the following week dependant on their rehabilitation goals.

**Results:** Seventeen patient's trialled an activity tracker for between 2 to 19 weeks dependant on time in the rehabilitation service. For patients that demonstrated an improvement in physical activity, increased step count ranged from 778 to 4508 steps per day.

All patients demonstrated a variable step count pattern with 7 patients demonstrating a sustained increase in average daily step count. Four patients sought to purchase their own personal fitness tracker at time of discharge to continue to monitor activity levels.

**Conclusion**: Activity trackers can be a useful adjunct for community stroke rehabilitation to demonstrate current physical activity level and increase awareness of the importance of healthy active lifestyles within long term condition management. Not all participants increased their activity levels while attending ECSS. Stroke impairment is frequently multi-factorial and often patients present with a range of significant co-morbidities impacting on their ability to engage in activity. For patients with significant upper limb impairment, trackers had to be located on the non-affected wrist to increase reliability of step count data. Trackers did not reliably measure step count data for patients with a very slow walking pace. The nature of health behaviour change is complex and the use of activity trackers was not initiated as a 'one size fits all' solution to promoting an increase in activity however, using the trackers in this way appeared to motivate some patients to focus on their activity levels and they successfully demonstrated an increase at time of discharge.











Academic and Clinical Central Office for Research and Development

Poster Abstract 28	
Title:	Success of technology-based cores in Edinburgh Clinical Research Facility
Authors:	Natalie ZM Homer <sup>1</sup> , Tom MacGillivray <sup>2</sup> , Duncan Martin <sup>3</sup> , Lee Murphy <sup>4</sup>
Affiliations:	<sup>1</sup> Mass Spectrometry Core, <sup>2</sup> Image Analysis Core, <sup>3</sup> Edinburgh Imaging, <sup>4</sup> Genetics Core, Edinburgh Clinical Research Facility, Edinburgh, UK

Technology is a driving force behind scientific advancements. When the Edinburgh Clinical Research Facility was founded in 1997 it took the visionary decision to include a number of expert technology-driven 'cores' to work alongside the clinical team. This multidisciplinary approach to enabling clinical research is unique to NHS Lothian and the University of Edinburgh. Here we present four cores (Genetics, Imaging, Image Analysis and Mass Spectrometry) as exemplars of how initial investment in technology by the Wellcome Trust Millennial fund for Clinical Research, underpinned by ongoing annual support from NHS Lothian R&D for key facility personnel, is a working model for research technologies in Edinburgh.

The success of the cores to date has depended upon many factors, but three major needs we each identify are: (1) cutting edge instrumentation that is well managed, (2) an effective team of expert scientists and technicians to develop and facilitate the technology and (3) an environment that can support the financial, administrative and study management needs of each core.

Operating under cost-recovery models, each core has updated technologies through income and successful grant funding and increased the size of their teams of scientists and technicians. The number of publications, the number of clinical research fellows that engage with the cores and the ongoing education and training that we provide continues to grow. Our expertise and researcher base now extends beyond NHS Lothian into national and international networks and collaborations.

Our cores support clinical researchers from many specialties including oncology, surgery, endocrinology and cardiology. As the technologies have been adopted by the research community we have seen the number of clinical and pre-clinical studies increase year on year, contributing directly to translational medicine.

To be successful technology-driven cores require substantial infrastructural support, expert organisation and professional management. These four cores have many indicators of success and, with ongoing commitment, will continue to provide technical and scientific expertise to the clinical research community.











Academic and Clinical Central Office for Research and Development

Poster Abstract 29	
Title:	Provision of immediate postpartum intrauterine contraception (PPIUC) in a UK maternity setting
Authors:	Michelle Cooper, Shiona Coutts, Frances McGuire, Anna Glasier, Sharon Cameron
Affiliations:	University of Edinburgh, NHS Lothian

**Aims:** To determine the feasibility of providing PPIUC across NHS Lothian maternity services and to evaluate the clinical outcomes of PPIUC in this setting (uptake, complications, method continuation, patient satisfaction).

### Methods:

#### Implementation

Obstetric doctors and senior labour ward midwives were trained in PPIUC insertion techniques. Phased introduction of PPIUC service across two maternity hospitals in region (total of 9000 annual births). Women received PPIUC information during routine antenatal contraceptive counselling. Their PPIUC intention and choice of device (copper IUD or LNG-IUS) was indicated on the maternity record. Devices were fitted during caesarean section (via uterine incision) or within 48 hours of vaginal birth (via long placental forceps) by maternity staff. All insertion procedures were logged to enable follow-up.

### Evaluation

Between 4 and 6 weeks' postpartum, a patient survey and clinical review (including thread check and transvaginal ultrasound) were conducted to determine device location, immediate complications and patient satisfaction. A follow-up telephone survey was performed at 3, 6 and 12 months' postpartum to identify late complications and method continuation. Regional birth data was collected from electronic databases to determine overall PPIUC uptake.

**Results:** A total of 569 successful PPIUC insertions were performed during the study period (294 intracaesarean, 275 vaginal). Midwives performed 65% of the vaginal insertions. In those receiving intra-caesarean insertion, there were 9 (3.8%) cases of suspected endometritis, 16 (5.4%) complete device expulsions and 11 (3.7%) removals due to placement concern. In the vaginal group, there were 7 (2.5%) cases or suspected endometritis, 93 complete device expulsions (33.8%) and 73 (26.5%) removals due to placement concern. There were no cases on uterine perforation in either group. Median satisfaction scores were 10/10 at initial review. Following device expulsion, 63% of women in caesarean group and 73% in vaginal group opted for re-insertion. Continuation of the method was 79.1% in caesarean group (at 12 months) and 82% in vaginal group (at 3 months).

**Conclusions:** This is the first study of its kind to evaluate site-wide provision of PPIUC at both caesarean and vaginal birth in a UK setting. A low complication rate was observed overall, although device expulsion was more common after vaginal insertion. This is expected to improve over time as inserters become more experienced. Improving access to this highly effective contraceptive method at the time of delivery is feasible in a UK setting, and may help in reducing unwanted pregnancies and short inter-pregnancy intervals.













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Poster Abstract 30	
Title:	criticalcarerecovery.com: the rationale, process, challenges and rewards of scaling up an NHS Lothian e-health innovation for patients and families after Intensive Care
Authors:	Dr Pam Ramsay
Affiliations:	University of Edinburgh

**Background:** Every year in the UK, over 120,000 people survive a stay in an Intensive Care Unit (ICU). Survival is associated, however, with a range of long-term physical, psychosocial and cognitive issues known as "Post Intensive Care Syndrome". Hospital stays are short, limiting opportunities for targeted rehabilitation<sup>1</sup> and, despite professional recommendations<sup>2</sup>, post-discharge follow-up and support is rarely provided<sup>3</sup>. Almost 25% of Scottish patients are readmitted to hospital within 3 months of hospital discharge<sup>4</sup>, and cost-effective community-based interventions are urgently required.

We previously developed, implemented and evaluated critical carerecovery.com in the Royal Infirmary of Edinburgh, using quality improvement methodology<sup>5</sup>. We used a synthesis of >120 interviews with ICU survivors in completed research and aimed to (1) provide patients and families with information and advice on Post Intensive Care Syndrome and (2) signpost community-based support e.g. vocational rehabilitation, Citizens Advice, psychological support, etc. The website was evaluated and refined using online questionnaires, semi-structured interviews with patients and family members (n=35) and a focus group with ICU staff. We subsequently received funding from the Health Foundation and Technology Enabled Care to spread our innovation to other Scottish ICUs.

Aims: To implement and scale-up the innovation to a further 5 Scottish Intensive Care Units

**Methods:** We developed a taxonomy of patient reported need, based on completed qualitative research and identified relevant community-based health and well-being resources from a Scotland-wide online directory of support (ALISS <u>www.aliss.org</u>). We identified clinical champions in 5 additional Scottish ICUs across NHS Lothian, NHS Borders, NHS Greater Glasgow and Clyde, NHS Grampian and NHS Highlands. We developed training and provided support in the use of a content management system, enabling them to upload sources of local support on their own dedicated website. We used in-built Google analytics to monitor website traffic.

**Results:** We experienced multiple technical and logistical issues around our planned scale-up activities, particularly around the engagement of local champions (we have therefore recently employed a part-time member of staff to upload relevant online content). Nonetheless, between the 1<sup>st</sup> of January 2016 and 2019, the website has been viewed by **20,463** visitors worldwide.39% of UK visitors were from Scotland; 58% from England; 2% from Ireland and 2% from Wales. Over 85% of visitors are new visitors, indicating currency and ongoing engagement with the website by patients and families.

**Conclusions:** The implementation and scale-up of digital healthcare innovations is highly complex and cannot be dependent upon busy clinicians. Nonetheless, digital innovations can rapidly reach new, large audiences, and constitute a powerful tool in the follow-up and support of ICU survivors following hospital discharge. Future work will include engaging with these audiences to develop and integrate more *individualised* support into the website.













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