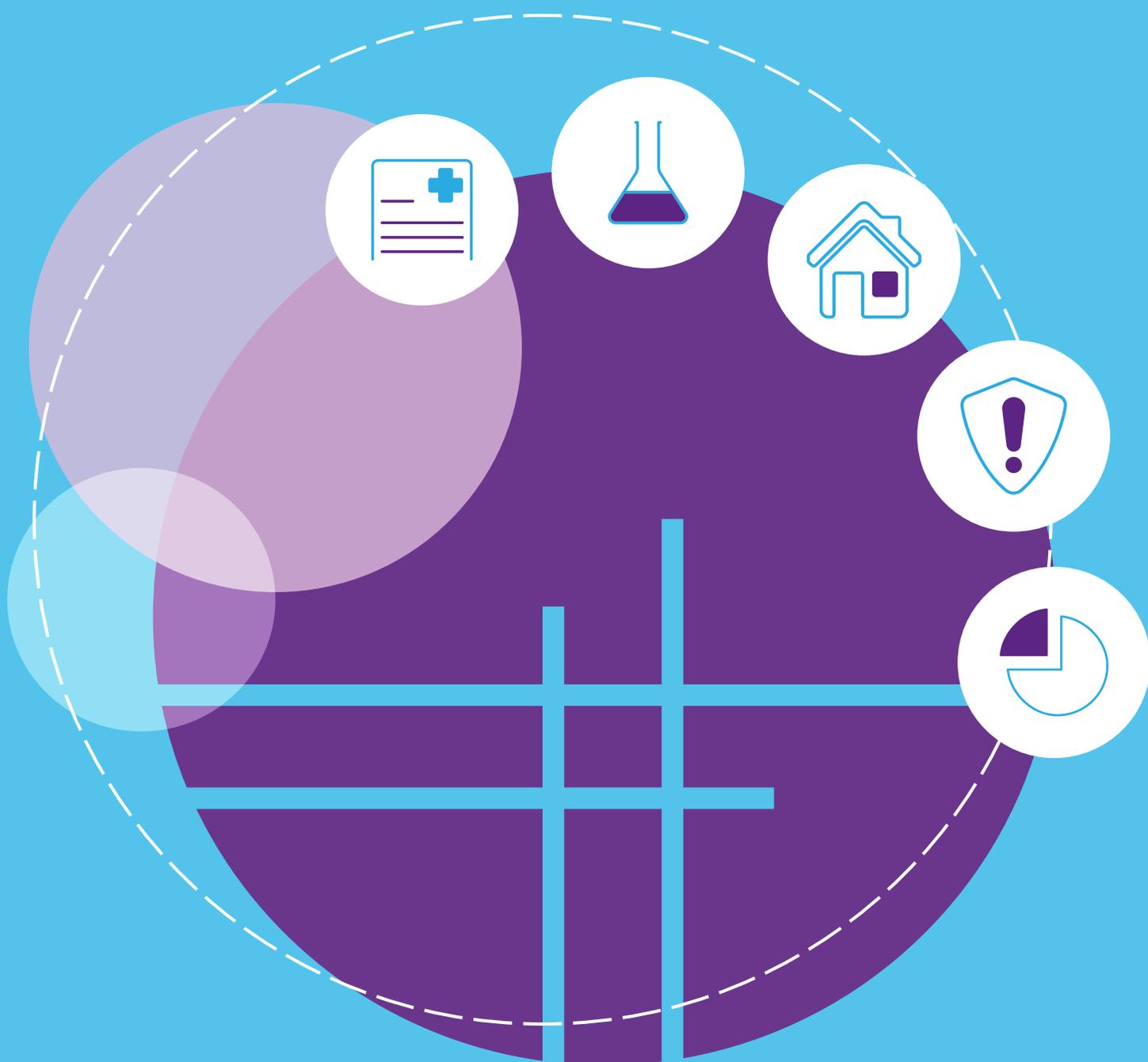


Scottish Dementia Research Consortium Impact Report



Scottish Dementia
Research Consortium



**Alzheimer
Scotland**
Action on Dementia

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Foreword

Minister for Mental Health



Dementia research in Scotland is crucial as part of advancing global efforts around, not only the prevention of and a cure for dementia, but also around the care, treatment and quality of life of people

living with the illness. Dementia is one of our foremost public health challenges and widening dementia research capacity in Scotland also benefits the development and implementation of dementia policy in Scotland. I congratulate the Scottish Dementia Research Consortium (SDRC) in building a community of interest and common endeavour in this field.

As part of the Scottish Government's 2017-2020 National Dementia Strategy, we continue to support the collaborative efforts of the SDRC in pooling the resources and the skills of the wide-ranging research community in Scotland and using this platform as a means of encouraging greater investment and research into dementia in Scotland. The SDRC has established a unique and ambitious role in bringing together researchers across the spectrum of dementia research.

I am pleased to note that the SDRC engages meaningfully with people with dementia and their carers. This principle is at the heart of everything we do around national policy on dementia, and people with dementia and their carers are represented across implementation activity in the range of National Dementia Strategy commitments.

As well as funding research opportunities through the Chief Scientist Office, the Scottish Government also contributes to UK-wide research funding programmes. In addition, we are working with others to develop a coordinated approach to promoting and recruiting to dementia clinical research trials in Scotland.

Among other achievements, this report notes that there has been an impressive £185 million of active grants awarded to Scottish Institutions into research on dementia since 2014. That achievement is a testament to the strength of the dementia research community here.

I welcome this report and congratulate SDRC members on their progress over the reporting year.

Clare Haughey MSP

National Dementia Carers Action Network (NDCAN)



We welcome this key research report mapping dementia research to date and informing new research developments towards prevention and treatment in the future. We value the research efforts being carried out

across Scotland, in collaboration with the rest of the UK and across the world, to improve dementia support and care practice. This will ultimately enhance the quality of life for all affected by dementia.

In NDCAN we campaign for positive change and improvements, both locally and nationally, and this must be supported by evidence based, quality research. It is vital that the experiences, knowledge and perspectives of unpaid dementia carers are included and considered in future research projects.

For too long, dementia hasn't been spoken about, but all over the world this is changing. When NDCAN members campaign for change and improvement for those currently living with dementia and their unpaid carers, it is vital to making a case to the decision makers and commissioners, that research is informing those directions. Scotland's researchers are working to find solutions to prevent, treat and eventually cure dementia and need our support. Involvement in research needs to happen prior to, or in early stages of, dementia. Understanding the value of research will also encourage more involvement. We very much support and endorse this key report.

Marion Ritchie, Committee Member
National Dementia Carers Action Network



Scottish Dementia Working Group (SDWG)



The Scottish Dementia Working Group (SDWG) appreciate the opportunity to contribute to the work of the SDRC and recognise the importance of bringing together the diverse range of dementia research in Scotland from

Fundamental Science to Diagnosis and the data generated through the Scottish Dementia Informatics Partnership.

As a national campaigning group of people with dementia, SDWG strongly advocate the need for ongoing research to ensure that people with dementia maintain their independence and connections within their communities. While we recognise that it is not currently possible to prevent dementia for those already diagnosed, we welcome ongoing research into

the diagnosis of all types of dementia in the hope that prevention may be possible for future generations.

In the interim, we hope that research will continue to provide new insights into how people with dementia live well. SDWG are passionate that people with dementia be viewed as partners in research to ensure that the voice of people with dementia is central to all stages of research from design to coproduction and that this receives appropriate funding. We are motivated by the updates on research developments outlined within this report and look forward to continuing to build connections with the research community.

Anne Macdonald
Scottish Dementia Working Group



Welcome

Prof Craig Ritchie— Chair, Scottish Dementia Research Consortium



I am delighted to welcome you to the first Scottish Dementia Research Consortium (SDRC) Impact Report. The SDRC was formed in 2013 as a membership-based organisation with the key aims of bringing together

Scottish-based dementia researchers from all disciplines and to promote Scottish dementia and brain health research interests at a national, UK, European and International level.

The data presented within this report contributes to these aims through showcasing Scotland's important position within the global dementia and brain health research environment and providing a benchmark as we develop our key contributions and leadership in the field over the coming years.

The SDRC works within five dementia and brain health research themes, which act as a nucleus for bringing together researchers and developing collaborations,

interdisciplinary research and innovative programmes. This report provides an overview of developments and future ambitions in each of these areas.

These themes also provide the platform to facilitate the inclusion of the voice and views of people with dementia, their families and those at risk of dementia, so that they are central to what we do.

SDRC will always value, promote and nurture our early career researchers. It is also important that all our membership identify with and feels an active part of the SDRC. Working together allows us to be a stronger movement towards key advancements in the development of care, detection, treatment and prevention approaches. The contribution from Carleen Smith, our highly valued SDRC staff member, outlines our priorities in building on our work to date and developing the engagement and active participation of our Membership.

This inaugural SDRC annual report will provide a key foundation for the pioneering development of the '*Scottish Dementia and Brain Health Research Strategy*'.

About Prof Craig Ritchie

Craig is the Professor of Psychiatry of Ageing at the University of Edinburgh where he also is Director of Edinburgh Centre for Dementia Prevention. He was elected Chair of SDRC in 2017 and has driven forward on his commitment to promote and grow that consortium to assist Scotland and Scottish-based researchers from all over the world to achieve its objectives and theirs.

His primary research interest is in the maintenance of brain health in mid-life to mitigate the risks of initiation and progression of degenerative brain diseases that may lead to dementia. To achieve this, he leads on the EPAD (European Prevention of Alzheimer's Dementia) Programme, the PREVENT Dementia Project and the Scottish Brain Health Register.

He was recently appointed as a Deputy Director of DPUK (Dementias Platform UK). He works clinically for NHS Lothian one day a week. He has published over 250 peer reviewed articles, conference abstracts and book chapters and attained almost £100M of competitive grant funding in his career to date.

SDRC Executive Committee

Prof Alison Murray



Alison is the Roland Sutton Professor of Radiology at the University of Aberdeen. She is Director of the Scottish Imaging Network: A Platform for Scientific Excellence (SINAPSE) a brain

imaging pooling initiative, an executive member of the SDRC and past-president of the Scottish Radiological Society.

Alison leads NHS molecular brain imaging in people with neurodegenerative diseases and dementia. She has a track record of brain magnetic resonance imaging research in the Aberdeen Birth Cohorts on factors that increase risk of cognitive impairment and conversely, what provides resilience to decline. She is passionate about the influence of early-life socio-economic circumstances on late-life brain health.

Prof Debbie Tolson



In 2013 Debbie was appointed as the Alzheimer Scotland Professor of Dementia and inaugural Director of the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland.

She is a registered nurse with an international reputation as a nurse leader and educator. Her professional standing is reflected in her Fellowship of the Royal College of Nursing, Honorary Fellowship of the Queens Nursing Institute Scotland and Principal Fellow Status with the UK Higher Education Academy.

As a founding member of SDRC she has championed a focus on early career researchers, and is particularly proud to have supervised, led and been involved in practice based research studies that are developing caring interventions and challenging approaches to advanced dementia care in Scotland, Europe and beyond.

Prof Frank Gunn-Moore



Frank studied Biological Sciences at the University of Edinburgh, and then achieved a PhD in Biochemistry at the University of Cambridge. After performing postdoctoral research at the Universities of

Bristol and Edinburgh, he started his own group in St Andrews, studying the development and survival of mammalian neurons.

Frank's approach to achieve this has been one of combining all three science disciplines, publishing in biological, chemical and physics based journals. The group have made major discoveries in understanding the early stages of Alzheimer's disease, pioneering new models and identifying a potential therapeutic targets. At St Andrews, Frank is the Head of the School of Biology. Frank is also Deputy Director of the Scottish Universities Life Sciences Alliance and has sat on many different funding agencies.

Dr Karen Watchman



Karen is an advocate of collaboration across all disciplines in dementia research. She is Senior Lecturer in Ageing, Dementia and Frailty and co-leads the Enhancing Self-Care research group

in the Faculty of Health Sciences and Sport at the University of Stirling.

With a focus on post-diagnostic support, intellectual disability and equality issues, she seeks diverse views of participants less often included in research. Her current work investigates non-pharmacological interventions with people who have an intellectual disability and dementia.

Karen is a member of Alzheimer Europe ethics working group and secretary of Down Syndrome Research Group for the International Association for the Scientific Study of Intellectual and Developmental Disability.

SDRC Executive Committee

Dr Louise Ritchie



Louise is a Lecturer in Dementia Research in the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland.

Louise is a psychologist with a focus on applied psychosocial research

that aims to improve the lives of people living with dementia, their families and people who care for them.

Dr Maggie Ellis



Maggie is a lecturer in Psychology at the School of Psychology & Neuroscience, University of St Andrews where she develops teaching, training and consultancy in dementia care, based on her research.

Maggie has been working with, and researching, the lives and experiences of people with dementia, their family members and professional caregivers for eighteen years and is dedicated to improving the experience for all concerned.

Maggie's main research focus is on identifying and utilising the spared communication skills in people at very advanced stages of dementia. For example, with Professor Arlene Astell she developed Adaptive Interaction, a method of supporting meaningful communication between caregivers and people with very advanced dementia. This work has generated much interest in the fields of both dementia research and care.

Prof Peter Connelly



Peter graduated M.B.,Ch.B from Glasgow University. He was an Old Age Psychiatry consultant based at Murray Royal Hospital, Perth from 1987 until his retirement in 2016. He led a successful bid, with his colleagues,

to establish the Scottish Dementia Clinical Research Network (now the Neuroprogressive and Dementia Network) in August 2008 and was the founding co-chair of the SDRC.

Peter has always had an interest in research particularly in answering questions relevant to people who have dementia.

In October 2014 Peter was made a Fellow of the Royal College of Physicians of Edinburgh and in 2015 an Honorary Professor in the Department of Applied Social Science at the University of Stirling.

Prof Richard Simpson



Richard Simpson OBE, FRCGP, FRCPsych, DPM, DipSHEB is currently an Honorary Professor in the Faculty of Health Sciences and Sport University of Stirling, attached to the Nursing Midwifery and Allied Professionals

Research Unit. He is also an Honorary visiting Professor at the School of Medicine University of St Andrews.

Richard was previously a GP and consultant psychiatrist. He founded and chaired the Forth Valley Primary Care Research Group and is also a founder member and former chair of Strathcarron Hospice. Richard was a member of the Scottish Parliament for thirteen years, including stints as a Minister in the first session government and a shadow Public Health Minister for nine years. His interest is in the politics of dementia.

Report introduction

The SDRC was formed in 2013 as a membership-based organisation with the key aims of bringing together Scottish-based dementia researchers from all disciplines and to promote Scottish dementia and brain health research interests at a national, UK, European and International level. This first impact report provides an update on the work of the SDRC to date and presents the results of an extensive mapping exercise of research in Scotland.

The SDRC currently has over 500 members, representing a network of researchers, policy makers and people living with dementia from across Scotland. Nurturing our early career researchers is of crucial importance to our future ambitions. This report presents data on our early career researcher community and features individual researcher spotlights within each of the themed areas.

A further aim of the SDRC is to ensure the voice and experience of people with dementia and their families are central to research policy and development. The following themed sections highlight how this is being taken forward within the different areas of dementia and brain health research. The final contribution from Carleen Smith, SDRC Officer, presents her ambitions in taking this forward into the coming year.

This report presents an overview of what we know, where we are now and future ambitions within each of the key areas of brain health and dementia research. The mapping data is then presented, highlighting Scotland's key contribution to global dementia and brain health research. This data will continue to be updated and presented within the annual SDRC impact report.

SDRC dementia research themes



What we know, where we are now and future ambitions within each of the key areas of dementia and brain health research.

- 1 — **Diagnosis**
- 2 — **Fundamental Science**
- 3 — **Living with Dementia**
- 4 — **Prevention**
- 5 — **Scottish Dementia Informatics Partnership**



1

Diagnosis

Professor Alison Murray Theme Lead

The diagnosis theme is about how conditions that can cause progressive brain failure and lead to dementia are diagnosed. Currently, a typical diagnosis involves speaking to a healthcare professional with someone who knows you well and answering questions about things you find difficult. This is often memory but also includes other aspects of life.

Diagnosis is important because this then determines whether there are any treatment options and what the likely prognosis, that is the course of the disease, will be. Most people and their relatives find this helpful. This also allows for the possibility of a person taking part in a clinical trial.

Diagnosis usually also involves tests such as blood tests, spinal fluid tests and brain scanning, depending on what the likely diagnosis might be.

There are many ongoing clinical trials and research studies that recruit patients in routine clinical care in order to find out the best methods for diagnosis now and in the future. Accurate diagnosis is also important if people are to be recruited to a specific clinical trial.

There are currently 150 researchers and 29 PhD students working within the Diagnosis theme across Scotland. Collectively, the researchers working in the theme have secured £69 million in grant funding and 264 publications in the past five years.

Research into diagnosis of conditions that can cause dementia is advancing all the time. This can include new ways of clinical testing of patients and coming up with more specific tests to be applied in clinical practice. New ways of brain scanning can involve anything from inventing new machines to new ways of analysing the scanning information.

Current research at the University of Aberdeen concentrates on two main areas. Firstly, understanding what makes people more vulnerable or more resilient to diseases that cause dementia by studying well-characterised people over a long course of time. Research has focused on the Aberdeen birth cohorts, including those born in 1921, 1936 and currently those born between 1950 and 1955.

Secondly there is a large group researching new drugs for Alzheimer's disease and frontotemporal dementia, who use structural and molecular imaging as biomarkers of disease and response to treatment. There are also laboratory-based scientists researching

new models of different diseases that can result in dementia in order to understand how these progress and any potential new treatments.

At the University of Edinburgh there are two main dementia-related initiatives. The first is the European prevention of Alzheimer's disease clinical trial occurring across multiple centres in Europe. The second is the Dementia Research Institute where research to understand the basic biological mechanisms of brain ageing and disease that causes dementia occurs.

In the future there are real prospects of dementia prevention by better understanding the risk factors and what can be done during life to reduce these. There are also new scanning methods being developed. For example, a completely new way of carrying out magnetic resonance imaging called fast field cycling MRI has been developed at the University of Aberdeen. There is also work on new radioactive tracers that can help with specific early diagnosis in Alzheimer's disease.

Early career researcher spotlight

Kotryna Baronaite, PhD student



I have joined University of Aberdeen as an Elphinstone Scholar and TauRx Ltd funded PhD student under the supervision of Prof John Storey and Prof Alison Murray. My project focuses on development of tau binding molecules for use as tau PET (positron emission tomography) probes.

This involves synthesis of a number of molecules which are then tested using a competitive assay. A selection of the most successful molecules can then be made and radiolabelled using tritium. This will then be used for an autoradiography study with tau transgenic mouse brain tissue at King's College London.

I hope that this could lead to a small animal PET study which would benefit the understanding of the specific binding of tau protein to my developed radioactive tracer. I expect that this will aid in the early detection, staging and monitoring of people with Alzheimer's disease, in addition to providing further insight within drug discovery areas.

I have completed my undergraduate degree in "Forensic Science and DNA" at IT Dublin University and Masters in "Analytical Chemistry (Drug Analysis and Toxicology)" at Robert Gordon University. The hope is to pursue my career in Alzheimer's disease and maintain a keen level of interest towards academia.



2

Fundamental Science

Professor Frank Gunn-Moore
Theme Lead

Scotland has a strong reputation in the fundamental sciences, particularly the study of all neurodegenerative diseases with a diverse range of world-class researchers. Testing of animal behaviour, the development of the magnetic resonance imager, genetically modified animals and neuronal stem cell technology all have their roots in the fundamental sciences in Scotland.

At present, their work spans from the atomic level of understanding of a potential drug target, to evidencing that humans are not the only mammals to show the chemical signs of dementia. Such a wide remit means that it can draw on the whole of the Life Sciences base in Scotland which numbers approximately 10,000 researchers in total.

Scottish academic publications in the field have highlighted major breakthroughs in our understanding of the mechanisms that underpin much of what we know about neurodegenerative diseases today.

This rich understanding has led to new and world-leading facilities that are aiming to translate this knowledge into potential new therapies. The concentration of drug discovery research in Scotland is unparalleled in Europe.

Scotland's fundamental sciences certainly punch above their weight in the field of dementia research, with current numbers of researchers exceeding 170, with the addition of over 40 PhD students. This includes one of

the prestigious Alzheimer's Society Doctoral Training Centres, uniquely combining the expertise from four Scottish Universities: Edinburgh, Dundee, St Andrews and Aberdeen.

This rich background has brought in over £65 million in the last five years in grants from a wide-range of funding sources. However, this is not the whole picture as the fundamental sciences by their nature are not just reliant on acknowledged neurodegenerative researchers.

Fundamental sciences can also draw on the expertise of all Life Science researchers in Scotland, plus the wealth and strength in depth of other disciplines including Chemistry and Physics, making it a truly interdisciplinary field. This cross-discipline approach has been recognised by the higher education institutions and the Scottish Government.

There has been a shift in who is performing this research. Research in this area had been confined to the university sector, with an extensive published literature on the work which has come from these studies.

These have provided major breakthroughs in our understanding of the mechanisms that underpin many of the neurodegenerating diseases.

This rich vein of fundamental knowledge has led to new and world-leading facilities in the efforts to translate this knowledge into potential therapies. The concentration of drug discovery research in Scotland is unprecedented in Europe. It is home to the European Lead Factory, Dundee Drug Discovery Unit, the National Phenotypic Screening Centre and the Kosterlitz Centre for Therapeutics. These provide examples of large amounts of funds from joint partnerships between Pharmaceutical Industries, Universities and the Government and totals approximately £200 million in investment.

External recognition of the depth and strength in the fundamental sciences has also come from attracting new funds and approaches to Scotland. An important example of this is the awarding of one of the new Dementia Research Institutes (DRI) in Edinburgh (focusing on the fundamental molecular determinates of neurodegeneration).

The DRI launch also led to pump-priming initiatives to promote collaborative research across Scotland. The DRI award was a part of the legacy from the G8 Dementia summit in 2013, with £250 million injection of funds into dementia research (other locations are three in London, one in Cardiff and one in Cambridge).

The gathering strength of fundamental science was acknowledged by the SDRC, with the 2019 annual conference in Glasgow focused on this theme. It was also recognised with the launch of the annual "Scottish Neurological Research Fund", resourced by the Scottish Government and RS Macdonald Charitable Trust. The purpose of this fund is to pump-prime collaborative research across Scotland's higher education institutions.

This solid basis indicates that research into the fundamental mechanisms that cause neurodegeneration will continue to flourish. Looking to the future we predict the development of additional interdisciplinary approaches.

Early career researcher spotlight

Dr Laura Aitken



I am currently a post-doctoral research fellow at the University of St. Andrews in Scotland. I earned my BSc. (Hons) in Pharmaceutical Chemistry from the University of Dundee (Scotland) in 2008 and received my PhD in Neurobiology from the University of St. Andrews in 2013.

After a brief spell in Industry I returned to St. Andrews to work with Prof. Frank Gunn-Moore, where my post-doctoral studies have been a progression of my PhD work "investigating protein-protein interactions involved in Alzheimer's disease and designing potential therapeutics against them".

Since 2013, I have characterised and developed several series of different compounds against a key drug target in Alzheimer's disease, as well as leading a large HTS European grant

collaboration; yielding two distinct analogue series of molecules which will shortly be entering "in vivo" pre-clinical trials.

Currently, there are no disease modifying therapies for Alzheimer's disease and the constant need to learn, improve and challenge our knowledge of the disease to achieve this has been a huge driving factor behind my research.

I am also a STEM ambassador who enjoys disseminating my research to the general public and inspiring the next generation of young scientists. My long-term aspirations include continuing to use this passion for research to contribute to the dementia field and forge my own path for an independent career in academia.

**3**

Living with Dementia

Professor Debbie Tolson
Theme Lead

A person's experience of living with dementia is unique and influenced by a range of factors. As dementia advances the needs of an individual and their family, changes and it is important that we understand the experience of dementia and generate an evidence-based understanding of how to support, care for and enable all affected by dementia to live the best life possible.

The Living with Dementia theme extends across studies that focus on any aspect of life and living, practice-based research, improvement science, health and integrated care services research, caring sciences including family caring, therapeutic and caring interventions and dementia education.

Research within this theme is about generating new knowledge that has potential for immediate impact that will improve lives and experiences of care and caring. It is also about finding evidence-informed ways to deliver on our National Dementia Strategies. If we can do this we will transform lives and keep Scotland at the forefront of innovations in dementia care, policy initiatives and dementia education.

Scotland leads the way globally in the involvement of people with dementia and their families in research activities. Our commitment to actively involving people with dementia in research has resulted in the creation of novel research approaches.

There are currently 138 researchers and 43 PhD students working within the Living with Dementia research theme across Scotland. Collectively they have secured over £5 million in grant funding and 135 publications in the past five years.

Collaboration across higher education institutions has proved key to ensuring our ability to produce high-quality, original and impactful research which makes a difference to the lives of those living with dementia.

Some examples of our interdisciplinary collaborations and current research are:

- Seminal research exploring the experience of dementia in employment led by the University of the West of Scotland and Heriot Watt University, with follow-on studies led by Napier with University of the West of Scotland and Heriot Watt University
- The role of music in maintaining wellbeing (Glasgow Caledonian University, University of Edinburgh)

- Delirium in the acute hospital setting (University of the West of Scotland, Glasgow Caledonian University and University of Edinburgh)
- Care in the advanced stages of dementia (Palliare) (University of the West of Scotland and 6 EU partners)
- Evaluations of specific initiatives such as football reminiscence interventions, individualised sensory interventions, complementary therapies, dementia dogs, dementia friendly walking football, dementia friendly choirs and a dementia friendly care home community (University of the West of Scotland)
- Development of new models of care such as person-centred care (Queen Margaret University)
- Relational co-operative care (University of Edinburgh)

- Communication in advanced dementia (Adaptive Interaction) and its behavioural and psychological impact (University of St Andrews)
- Non-pharmacological interventions for people with learning disability and dementia (University of Stirling)
- Research into the role of design, people spaces and places neighbourhood study (University of Stirling)

One of our key aims is to strengthen interdisciplinary research and build inclusive cross institutional teams. We are keen to secure funding that accelerates success and impact of early career researchers and studies that advance and propel caring innovations including those that sustain family caring and use of leading-edge technology.

Early career researcher spotlight

Dr Bryan Mitchell



I am a qualified Complementary Therapist and completed my PhD full time (2014-2018) at the University of the West of Scotland. My funding was initially from an independent care home provider however I then had to self-fund before, fortunately, Alzheimer Scotland were able to help.

As a new post doctorate researcher I was pleased to reach the final stage of a competitive research fellowship funding application with Alzheimer's Society. SDRC networks have since been supporting me to make funding applications to build on my doctoral action research study.

During my doctoral research I collaboratively developed and tested a personalised complementary therapy intervention with nursing home residents with advanced dementia. To date funding success has proved elusive, despite the encouraging evidence from my research of a reduction in neuropsychiatric symptoms associated

with stress and distress and positive feedback from individuals, staff and family included in the study.

I remain in contact with nursing homes that have opted to embrace the findings from my PhD, actively incorporating complementary therapy within nursing home practice. Encouragingly there is now recognition from different groups and calls for research into the use of complementary therapies in dementia care.

Since completing my PhD I have worked as a research assistant at University of the West of Scotland, making my mark by getting the "Class in the Bag" research based education resource ready for market.

More recently, I have secured a permanent post at the University of the West of Scotland as a lecturer where I contribute to and deliver the BA (Hons) Integrated Health and Social Care and MSc leading People Centred Integrated Care programmes.



4

Prevention

Professor Craig Ritchie
Theme Lead

Prevention is a broad concept in health care, often divided into three processes. Primary prevention where we attempt to ensure that the disease never starts (such as immunisation or vaccination), secondary prevention where we attempt to stop clinical symptoms developing in a person with evidence of early disease and finally tertiary prevention where we try and help people with symptoms not develop significant impairments.

Historically in dementia and degenerative brain disease work we have been focused on tertiary prevention with post diagnostic support and medications. However, with greater understanding of the science of degenerative brain diseases, we are now able to detect early disease and are getting better at working out what is likely to happen in the future.

Secondary prevention in degenerative brain disease is a massive area of research worldwide and in Scotland we lead several of the main projects globally that are opening the door to real progress in clinic and at a population level.

The numbers of people with end-stage degenerative brain disease (or dementia) is increasing in all parts of the world, primarily because people are living longer. As we begin to understand how degenerative brain diseases start, develop and who is most at

risk, we can put in place detection techniques (working with our colleagues in the SDRC Diagnosis theme) and then put in place plans to mitigate the risk of further decline. If we can do this effectively decades before the symptoms develop then we can prevent the disease progressing to dementia. Imagine a world where we have prevented dementia!

This work mainly includes the undertaking and coordination of cohort studies (a group of people studied over time) where we can learn about disease progression and how this is related to factors like lifestyle, medical comorbidities and genetics. At the same time as this we can also learn how best to most accurately detect disease through using biomarkers like brain imaging, blood tests or sampling spinal fluid.

Over time in SDRC we will coordinate our cohort studies and their findings, with the information we are gathering from the 'real

world' through the roll out of the Scottish Brain Health Register (SBHR) which is a key part of the SDIP of SDRC.

This may be the biggest single area of research in the coming decades ahead. In addition to being a theme, it is an objective upon which all other themes will deliver knowledge. This can include fundamental science shining a light on important disease mechanisms or means of detection or the living with dementia theme that will influence implementation of findings into practice.

There are currently 153 researchers and 13 PhD students working within the Prevention research theme across Scotland. Collectively they have secured over £40million in grant funding and 233 publications in the past five years.

The main advance in the field over the last 10 years has been the convincing evidence that degenerative brain disease starts about 30-40 years before the first signs of dementia appear.

Detecting early stage disease can lead to interventions that will affect the course of disease using both risk modification and direct interventions (for example new medicines). The most recent advance has been the establishment of several large cohort studies. People are becoming part of a study group in mid-life, which will add to the evidence base and allow us to develop a much more detailed understanding of risk and disease interactions that cannot currently be uncovered.

In the coming years the SDRC must engage all Scottish researchers working in the prevention field. We are currently focused on two projects which are led from Scotland. These are EPAD (European Prevention of Alzheimer's Dementia) and PREVENT Dementia which has centres in Glasgow, Tayside, Edinburgh and Aberdeen. The further development of the SBHR will help gather real world data and enable us to test ideas that emerge from the research studies in the general population.

Early career researcher spotlight

Stina Saunders, PhD student

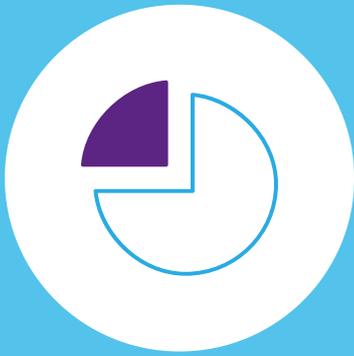


I am a doctoral candidate at the University of Edinburgh Centre for Clinical Brain Sciences and a fellow at the EPAD project.

Before my PhD, I completed my postgraduate studies in Clinical Psychology at the University of Tartu in Estonia, focusing on adjustment disorders and stress reactions, and at the University of Edinburgh, researching the role of attachment in living with dementia. Aside from my doctoral work, I am involved with European Medicines Agency led work around patient preferences and patient reported outcomes measures in clinical trials.

In my PhD, I am looking at the impact of diagnostic

test disclosure in the mild cognitive impairment population. My PhD study explores how diagnostic test results are communicated to patients in Memory clinics, looking at how information given to patients about their brain health could impact the patients' psychological reaction to their diagnosis. After completing my PhD, I hope to continue working in the pre-dementia stages of Alzheimer's disease, improving the experiences of people dealing with uncertainties of disease progression.



5

Scottish Dementia Informatics Partnership

Professor Craig Ritchie
Theme Lead

The SDIP is a project that makes use of a wealth of data that have the potential to address fundamental questions about the healthcare of people living with dementia and at a high risk of developing this condition.

In Scotland, when a person uses the national health and social care services, all the information that is generated from their visit is stored in different systems. Scotland is producing a significant amount of clinical data about people living with dementia and healthcare in general. Joining this information together offers great opportunity to dementia research. This theme is working on bringing this information together to also provide a basis to test new health informatics technologies. This will lead to Scotland being an early adopter to innovations that may help deliver a better standard of care or insight to a person's dementia.

The ability to access and analyse this data will provide the research community with a population-level insight into living with dementia and how health risks may lead to poor brain health, allowing a range of research to be conducted, from descriptive statistics, to auditing of service provision, to phase IV trials. At a higher level, SDIP, as its own project, will hold Scotland as a case study and report how data linkage, and the integration of data, can be used to address national healthcare challenges.

There are currently 28 researchers and 6 PhD students working within the SDIP research theme across Scotland. Collectively they have secured over £800,000 in grant funding and 20 publications in the past five years. It should be highlighted that many of those classified as working in other themes are contributing to this important area of research.

SDIP is a national project and will link data on the Scottish population. Our current research and strategy has been focused on NHS Lothian, so that we can apply a relatively small-scale, proof of concept of SDIP to identify experiences, barriers and challenges that can help inform the national rollout.

The foundation dataset for SDIP will be represented by the SBHR. This is a research interest register that connects people to dementia and brain health research and is situated as part of a memory clinic service in NHS Lothian, meaning that all patients under the service's care receive the opportunity to take part in research and to be kept informed on what research is being done.

By signing up to the register, people have the opportunity for their demographic and medical details to be collected and recorded into the register, so that they may anonymously be reviewed and analysed as part of SDIP. Furthermore, if that person takes part in a study, data generated about them through that study would also be recorded into the register.

Our future work is dedicated to national rollout, informed by our experiences and findings of our work in NHS Lothian. The SDIP strategy is to introduce SBHR to NHS Grampian, Tayside and Greater Glasgow and Clyde throughout 2019. In this way, the foundation dataset will reach to and represent the largest hospital sites and boards across Scotland. Best practice manuals and implementation strategies are being built on the basis of evaluation work completed to date

and working with key memory impairment clinicians at the three sites to ensure lessons learnt from the pilot site are incorporated into the next phase.

SDIP also works closely with a number of stakeholders and a key focus for the coming months is gathering input on use cases from each group. The stakeholders of focus are patients and the public, and industry. We will be working with the SDWG and NDCAN to understand their views on research opportunities, preferred communication methods and timing of introductions to research in diagnostic journeys. We will also be developing end user beneficiary reports to demonstrate the potential benefits anonymous data access may have for industry partners.



Early career researcher spotlight

Catriona Ingram

I am currently a ST4 Higher Trainee in Old Age Psychiatry in the West of Scotland. I have also recently spent a year doing the Scottish Clinical Leadership Fellowship working with the Chief Medical Officer for Scotland in the Scottish Government and with Healthcare Improvement Scotland.

Through my time in this fellowship it was evident that having relevant data was incredibly valuable in the development of health services. Likewise I see in my day to day clinical work that better quality up-to-date data could be extremely useful in terms of the information that could be presented to patients and used in clinical decision making.

I was therefore really excited to hear about the development of the SDIP which aims to allow us to use data more effectively to improve clinical care, widen research opportunities for people living with dementia and help to inform policy.

So far I have been involved with the initial evaluation work of the Edinburgh Memory Assessment and Treatment Service and how they are recruiting to the SBHR. This has involved interviews with staff and qualitative thematic analysis. I have also discussed the development of SDIP with relevant groups such as the Focus on Dementia Team at Healthcare Improvement Scotland and Old Age Psychiatrists in the West of Scotland.

I have contributed to developing questionnaires to people currently on the SBHR which we hope will provide useful feedback on their experience of being on the register. I look forward to continuing to contribute to the evaluation of SDIP as the project progresses.

Mapping Scotland's key contribution to global dementia and brain health research

The SDRC conducted an extensive mapping exercise of Scottish research across all dementia disciplines over the past five years. The results highlight the significant contribution and key position of Scotland to global dementia and brain health research. Scotland has been awarded over 400 grants totalling £185 million of funding during this time.

We have 700 dementia researchers, with an additional 150 doctoral training students. They are working across all the disciplines of dementia and brain health research and presented here within the SDRC themes.

This mapping data will continue to be updated and reported on an annual basis. The results presented below highlight our key position and provide a baseline to show where Scotland's contribution to dementia and brain health research can grow over the coming years.

Funding levels and sources

Figure 1 shows that grant funding has increased year on year, until 2018 where there was a decrease. This is in large part due to a small number of very large grants awarded in 2016 and 2017.

Looking at grants based on the total number awarded, Figure 2 shows this has been consistent over this time period.

Continuing to update the mapping data will allow the SDRC to monitor this situation on an ongoing basis and provide an understanding of patterns and where particular efforts should be focused to increase grant funding.

The amount of grant funding awarded has been split across the relevant SDRC theme in Figure 3. This highlights that the levels of funding available to dementia research varies across the disciplines.

The level of resources available to Prevention and Diagnosis themes are consistent, with Fundamental

science having access to the greatest investment and Living with dementia able to draw from more modest funding streams.

“The levels of funding available to dementia research varies across the disciplines.”

Figure 4 shows the role of public, charity and private funding sources in the overall dementia and brain health research picture. This also highlights the important contribution of European funding. The largest proportion of grant awards come from the public sector, such as the Medical Research Council. The second largest source of funding is the charity sector.

Figure 1: Grant award and funding by year

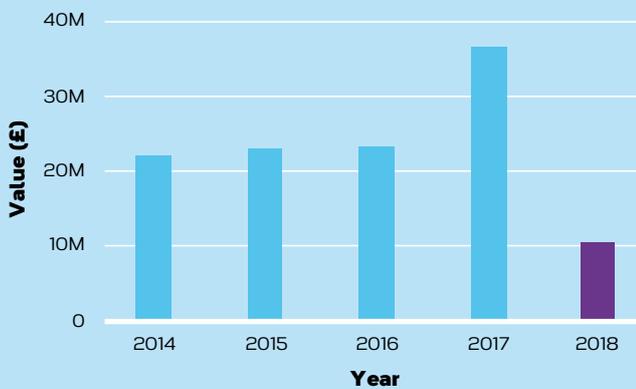


Figure 2: Total grants awarded by year

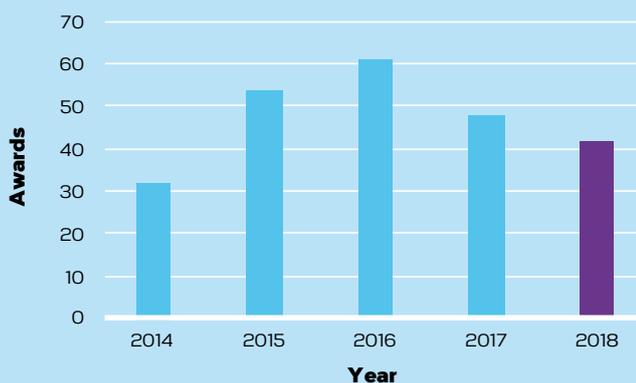


Figure 3: Grant funding by SDRC Theme

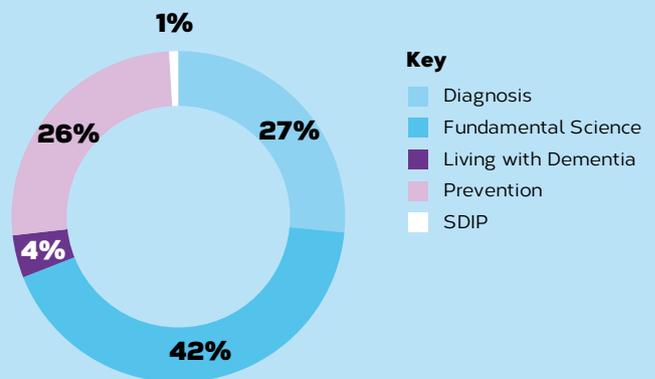
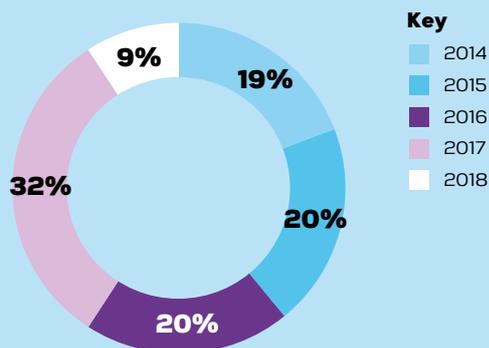


Figure 4: Sources of funding



Researchers in Scotland

Scotland has attracted such a high amount of investment in dementia research grants due to the experience and expertise of the researchers in our higher education institutions.

“Scotland has a wealth of established and early career researchers.”

There are 700 researchers working in dementia and brain health research in Scotland. Figure 5 shows that there is an even spread of researchers across most of the SDRC themes. Whilst the SDIP researchers are shown to only make up 4% of

this picture, in reality many of those classified as working in other themes are contributing to this important area of research.

Scotland has a wealth of experienced and early career dementia and brain health researchers. Whilst a large proportion of dementia researchers in Scotland are well established and have a worldwide reputation, there is also a promising future with a significant group of PhD students and early career researchers.

Figure 6 highlights the proportion of researchers at each phase of the research career pathway. Figure 7 shows the breakdown of PhD students by SDRC theme.

Figure 5: Researchers by SDRC theme

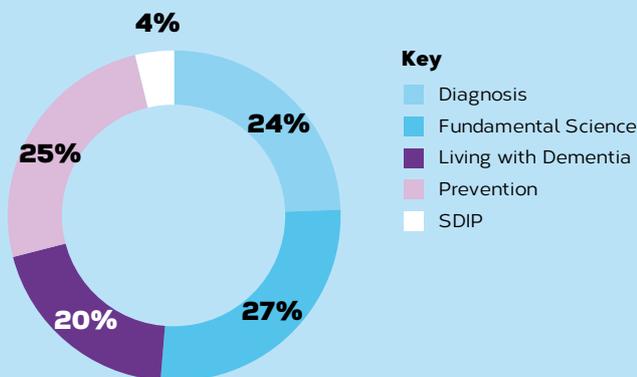


Figure 7: PHD students by theme

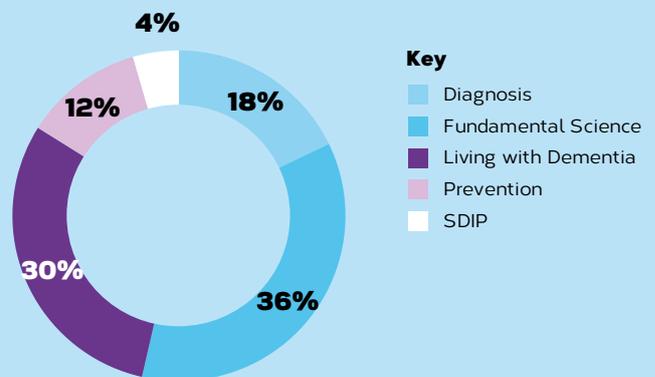
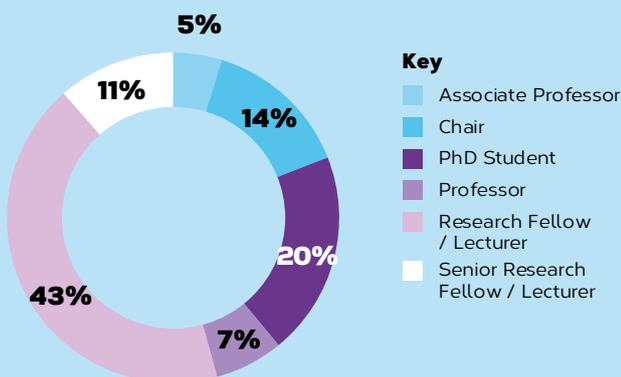


Figure 6: Researchers by stage of career



Published papers

In addition to grant awards, this mapping project also analysed the publications of our research community in Scotland. Our position as a world-leader in dementia and brain health research is evidenced by this output.

Figure 8 shows that our researchers have led or contributed to 962 publications since 2014.

“These publications have been cited over 7,600 times.”

Despite slight year on year fluctuations, the number of papers published has increased significantly between 2014 and 2018. These papers have been cited over 7,600 times, which highlights their impact and breadth of their reach and influence.

Figure 9 shows the breakdown of publications by SDRC theme based on the area of research for the contributing authors.

Figure 8: Published papers

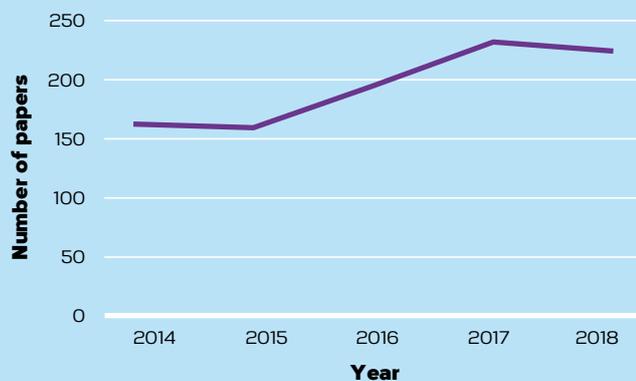
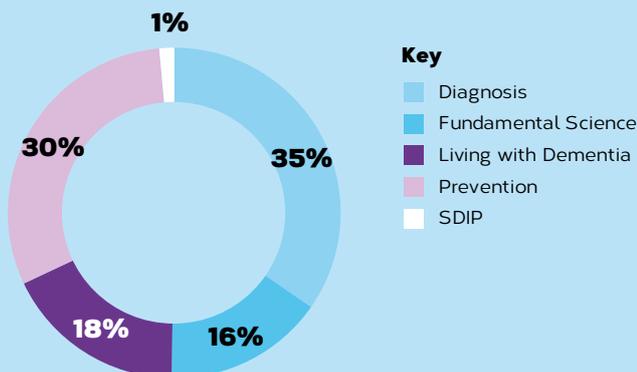


Figure 9: Published papers by SDRC theme



International collaboration

This report has demonstrated the experience, expertise and impact of Scotland’s dementia and brain health researchers. International collaborations are also an important area to consider in understanding our global reach.

Our researchers have collaborated with over 1200 researchers around the world, from 43 countries in 433 institutions over the past five years.

Figure 10 shows the top 10 countries that Scotland have collaborated with most often since 2014.

Figure 11 highlights that Scottish researchers collaborate most frequently with researchers in the UK than any other individual country, but collectively dementia researchers in Scotland collaborated more often with researchers outside the UK.

This highlights that our researchers are very much embedded within the global dementia and brain health research environment.

Figure 10: International collaborations

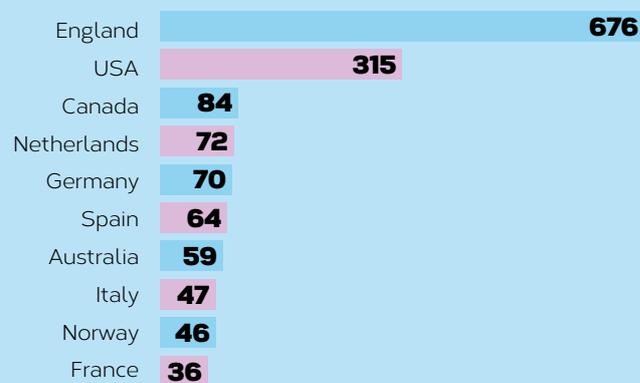
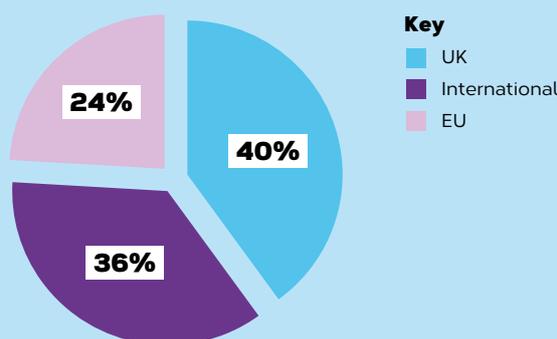


Figure 11: Proportion of collaborations

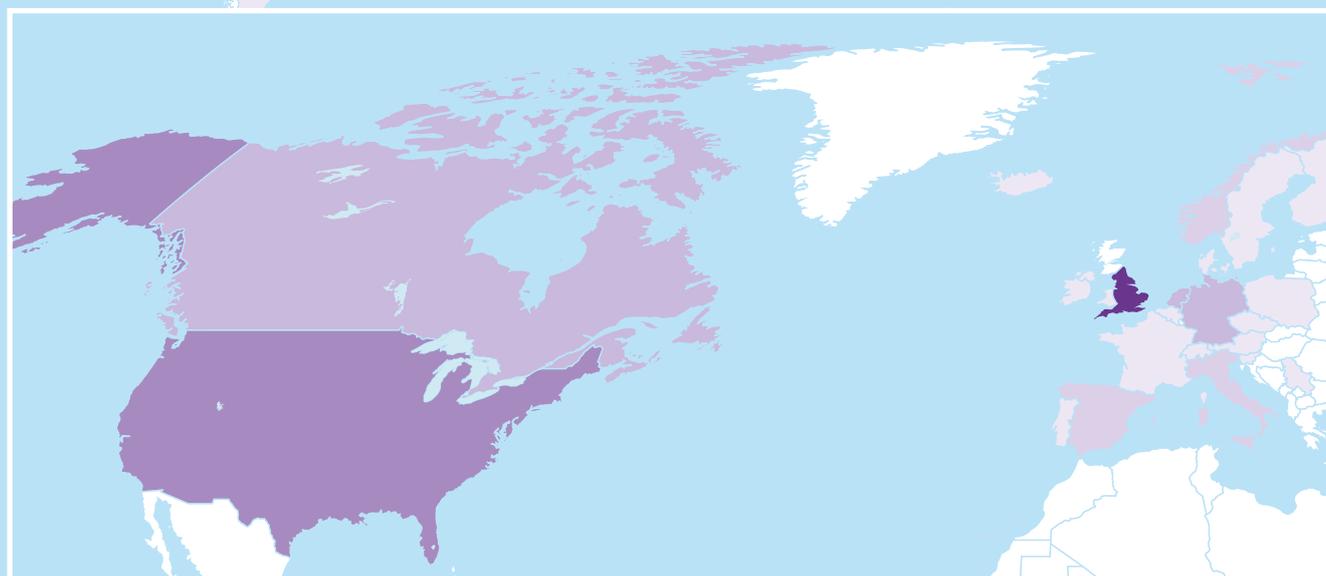
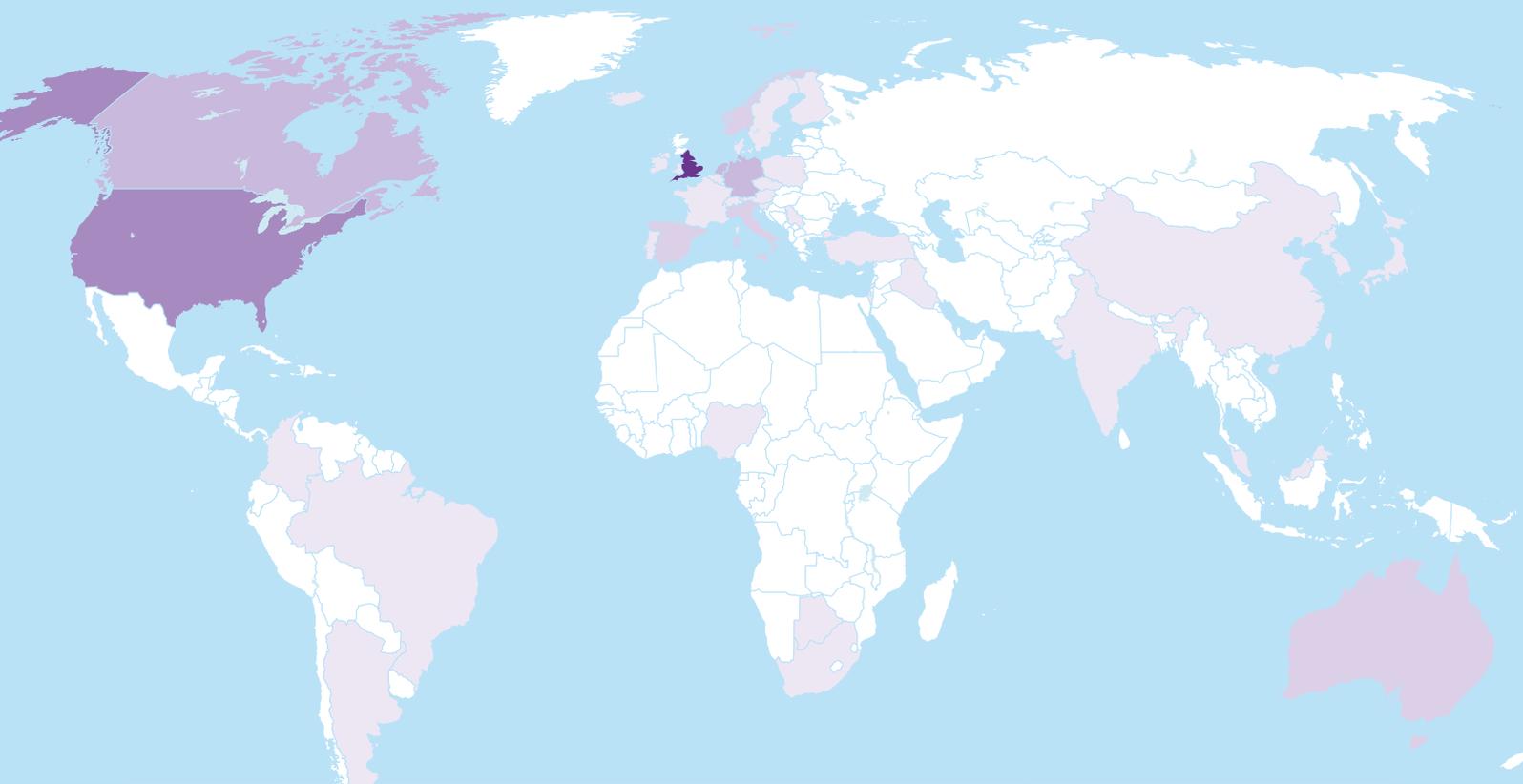


“Scotland’s researchers global reach is notable worldwide.”

Figure 12 highlights the key areas of international collaboration. The darker the shading of the country, the higher the number of collaborations

with Scottish based dementia and brain health researchers that have taken place. Figure 12 highlights that the greatest number of Scotland’s collaboration are with the countries in Europe and North America. Nonetheless, the extent of Scotland’s researchers global reach is notable worldwide.

Figure 12: International collaboration, inset: European and North American collaboration



Message to membership

Carleen Smith—SDRC Officer



I have been in the role of SDRC Officer since July 2018, and a lot has happened in such a short time. I welcome this opportunity to give an overview of SDRC activity over the past few months and highlight some of our plans and ambitions for the coming year.

My biggest task to date has been the mapping of dementia and brain health research in Scotland. It has been a wonderful project to start off with, as it has allowed me to see first-hand the depth and breadth of research happening across Scotland and its impact. This mapping data will provide a benchmark to monitor and support future research and collaboration across institutions and disciplines.

Now that the SDRC have a full picture of dementia research activity in Scotland, we have an opportunity to showcase this in a way we have never previously been able to do. This will greatly support our membership engagement strategy in that we can use our website and social media more to highlight researchers and ongoing projects, and update followers more regularly of SDRC activity.

As well as developing our online presence, I am looking at the ways the SDRC can create opportunities for researchers to meet more regularly in person. Some of my current projects have been to support the establishment of the Scottish Cognitive Outcomes from Brain Injury Consortium and the development of a group on Virtual Reality in Dementia.

These approaches allow the experts from higher education institutions and other key stakeholders to share their research and contribute ideas to the development of future research and collaborations.

The SDRC membership has grown in the past 12 months to over 500 members. In the upcoming year, I plan to get to know more about our membership and find out how SDRC can support greater active engagement.

Another key aim of the SDRC is to ensure people with dementia and their families are at the forefront of everything we do. You have read about how we are currently doing this within our research themes in this report.

I am eager to explore ways in which the SDRC can further develop this engagement. I will be exploring and consulting on ways in which people with dementia and their families can become more involved in the work of the SDRC - not only as participants in research studies, but by taking an active role in developing and influencing the direction of research.

I have immensely enjoyed supporting the growth of the SDRC over the past year. I am delighted with what we have achieved in this time.

I would like to extend my deepest gratitude for the tremendous support of the SDRC membership, Executive Committee and colleagues at Alzheimer Scotland.

I look forward to continuing to work with you all and to more amazing achievements in the coming year.

The SDRC is supported by



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