

Scottish Dementia Research Consortium

Annual Report 2021/22



**Alzheimer
Scotland**



Scottish Dementia
Research Consortium

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Contents

Foreword	1
Welcome	2
SDRC Executive Committee	3
Introduction	5
About the Scottish Dementia Research Consortium	6
SDRC dementia research themes	7
Diagnosis	9
Fundamental Science	11
Informatics & Technologies	13
Living with dementia	15
Prevention	17
Mapping Scotland's key contribution to global dementia and brain health research	19
Alzheimer Scotland Brain Tissue Bank	25
Scottish Brain Health and Dementia Research Strategy	26
Brain Health Scotland	27
Expert Hub	28
Feedback from the SDRC Conference 2021	29
Message to membership	31
Become an SDRC member today	32

Figures

1. Grant income by year	20
2. Grant award by theme (£)	20
3. Grant income by year by theme	20
4. Funding sources by location	21
5. Funding source location by year	21
6. Funding source by type of organisation	21
7. Funding source by organisation by year	21
8. Proportion of active researchers by theme	22
9. Researchers by career stage	22
10. PhD students by theme 2020	22
11. Number of publications by theme in 2021	23
12. Number of publications by year	23
13. Top 20 Country Collaborations	24
14. Collaboration by Region	24

Foreword

National Dementia Carers Action Network (NDCAN)

The National Dementia Carers Action Network (NDCAN) was founded in 2011. We are a national campaigning and awareness raising group that enables the voices of carers to be heard and helps raise awareness of the issues which affect our lives. All our members are carers or have previously cared for people with a diagnosis of dementia who live in Scotland. We are grateful for the opportunity to be engaged with and involved in the valuable work of the Scottish Dementia Research Consortium (SDRC). NDCAN members have their own research subgroup which gives us the chance to learn about various research approaches, research theories and ethics. We understand and value the importance of the work of the SDRC, and we would like to congratulate them on another positive and successful year. We really look forward to working together in the future.

Scottish Dementia Working Group (SDWG)

The Scottish Dementia Working Group (SDWG) is national involvement group for people with dementia and supported by Alzheimer Scotland. We are a member led group and are involved in awareness raising and national campaigning for people with a diagnosis of dementia in Scotland. We fully support dementia research in Scotland and consider research as an area of priority both nationally and internationally. The SDWG keep members informed of the latest developments in research through regular meetings with our research subgroup, which also gives members the opportunity to take part in research projects. We have invaluable lived experience as people who have a diagnosis of dementia, and we believe that it is essential for the voices of people with dementia to be heard and included in discussions about dementia research. We would like to congratulate the Scottish Dementia Research Consortium on their annual report and another year of outstanding work.

Welcome

Prof Craig Ritchie – Chair, Scottish Dementia Research Consortium

I am delighted, as ever, to provide a foreword to the 2021 SDRC Annual Report. Our year in review illustrates clearly how the strength of dementia and brain health research in Scotland continues to grow. The fact though that this growth now has a clear route to impact through the launch and delivery of the world's first Brain Health and Dementia Research Strategy is unarguably our greatest achievement as a community of clinicians, researchers, people living with dementia and numerous other stakeholders.



Perhaps inevitably as the world remained abnormal and persistently virtual in so many ways – the necessary engagement in strategy delivery was affected. Now that life is thankfully returning to normal, there is a palpable acceleration, drive and steer for the ambition and the objectives of the strategy to become a core and uncompromised part of the Scottish Brain Health and Dementia ecosystem we have so carefully and thoughtfully crafted over recent years.

NHS engagement remains a huge challenge, an organisation 'on its knees' through the amplification of pre-existing stresses by the pandemic makes innovation and ambition even more important but more difficult to achieve. Our dedication and focus to improve the well-being of people living with dementia and preventing it through primary and secondary prevention policy and practice though has not been dulled despite the challenges.

In this report, we hear from all the themes and once more recognise the value and importance of our early career researcher community. More and more they form the backbone of SDRC. Our membership has grown now

to around 800 people with the biggest increase being in ECR membership. Our grant income has increased again back to pre-pandemic levels and lets expect it to start growing substantially as the strategy takes hold and our work force planning ensures we attract and retain the best people into and in all our superb Scottish universities. Publication numbers dropped a little in 2021 – maybe that's because we weren't chained to our desks like we were in 2020 – but per capita we still substantially influence above our weight and our global reach with academic partners across the world highlights how connected the Scottish research community remains to the rest of the world.

2022 will be an amazing year for us – the strategy's objective of making research relevant and rapidly implemented will be delivered upon. People living with dementia and people at risk of dementia will start to really and truly 'feel' that connection between research and care, no more Ivory Towers and research for the sake of research.

As researchers and academics, we are in a truly privileged position to be able to make a difference, sometimes it's hard to see that when the day to day grinds us down but the vision of SDRC is to create that world for all of us to realise that what drove us to be researchers is still possible to achieve.

At the end of the day, all SDRC wants to do is to build a place in Scotland where everyone gets to be the best version of themselves. We may not be there yet but I certainly feel we are getting there .. together.

SDRC Executive Committee

Prof Craig Ritchie

Craig is the Professor of Psychiatry of Ageing at the University of Edinburgh, Director of Edinburgh Centre for Dementia Prevention and Director of Brain Health Scotland.

His primary research interest is the maintenance of brain health in mid-life to mitigate the risks of initiation and progression of degenerative brain disease that may lead to dementia. He is Chief Investigator on the PREVENT Dementia and European Prevention of Alzheimer's Dementia Research Programmes.



Dr Jennifer Macfarlane

Jennifer is a Clinical Scientist based at Ninewells Hospital, Dundee, and Director of SINAPSE (Scottish Imaging Network: A Platform for Scientific Excellence) a research pooling group which brings together clinical and academic expertise in imaging research throughout Scotland, encouraging a multidisciplinary, collaborative and supportive approach to tackling Health and Wellbeing.

Her interests include functional neuroimaging and breast magnetic resonance imaging (MRI).



Dr Leah Macaden

Leah is a Senior Lecturer in Nursing at the University of the Highlands and Islands (UHI) in Scotland. She is a Churchill Fellow in recognition of her leadership and expertise in designing innovative approaches to dementia education for workforce development in health and social care. Her research focus is on using technology to equip and support people living with dementia and dementia education.



Dr Mario Parra Rodriguez

Mario graduated as a Medical Doctor in 1993 and as a Clinical Neurophysiologist in 1997. He worked at the Cuban Neuroscience Centre and at different University Hospitals in Cuba and in Colombia.

Mario was as an Assistant Professor in Psychology at Heriot-Watt University, Edinburgh from 2015 until 2018. He is currently a Senior Lecturer in Psychology at the University of Strathclyde, Glasgow.



Prof Debbie Tolson

Debbie is the Alzheimer Scotland Professor of Dementia and Director of the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland.

As a registered nurse, she is committed to practice-based research and best research involvement practice. Current studies include advanced dementia, family caring and living with young/late onset dementia.



Prof Frank Gunn-Moore

Frank is Head of the School of Biology at University of St Andrews and Deputy Director of the Scottish Universities Life Sciences Alliance.

He combines all three science disciplines in leading a research group that has made major discoveries in understanding the early stages of Alzheimer's disease, pioneering new models, and identifying potential therapeutic targets.



Dr Tom Russ

Tom trained in medicine and psychiatry in Edinburgh, the Highlands, and London and completed a PhD in dementia epidemiology at the University of Edinburgh.

He is a consultant psychiatrist in NHS Lothian, Network Champion of the NRS Neuroprogressive and Dementia Network, and Director of the Alzheimer Scotland Dementia Research Centre at the University of Edinburgh.



Stina Saunders

Stina is a PhD student at the University of Edinburgh looking at risk disclosure in the mild cognitive impairment population, this work stemmed from the European Prevention of Alzheimer's Dementia (EPAD) programme. Additionally, Stina is developing a personalised outcome measure (ePSOM) for use in clinical trials. Stina works at the University's Centre for Clinical Brain Sciences.



Dr Terry Quinn

Terry holds the post of Reader and Honorary Consultant Stroke Physician in the Institute of Cardiovascular and Medical Sciences, University of Glasgow. He is passionate about evidence-based practice and raising standards in clinical research.

Terry has a broad research portfolio, which he combines with active teaching and clinical commitments.



Dr Louise Ritchie

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

She is a psychologist with a focus on applied psychological research that aims to improve the lives of people living with dementia, their families and people who care for them.



Dr Sophie Bradley

Sophie is an Associate Director in Translational Neuroscience at Sosei Heptares, an international biopharmaceutical company focused on the development of G protein-coupled receptor (GPCR) targeted therapeutics.

Furthermore, Sophie is an Honorary Senior Research Fellow at the University of Glasgow, where her research is focussed on exploring the role and therapeutic potential of GPCRs in neurodegenerative disease.



Committee Changes

Since last year, there have been some changes to the SDRC Executive Committee. Professor Alison Murray, Diagnosis Theme lead, has now retired from clinical work and stepped down from SDRC. We wish to thank Alison for her immense contribution to SDRC and more generally to the dementia research ecosystem in Scotland. We are delighted to be joined Dr Jennifer Macfarlane, and look forward to working with her.

In the Living with Dementia theme, Dr Maggie Ellis from the University of St Andrews has left and we appreciate her tremendous commitment to SDRC, and congratulate her on her receipt of an MBE for services to people with dementia. A warm welcome to Dr Leah Macaden from the University of Highlands and Islands who has joined us this year.

Introduction

Welcome to the Scottish Dementia Research Consortium Report 2021/22.

The purpose of this report is to showcase and celebrate the wonderful work of the Scottish brain health and dementia research community from the past year.

The first section of the report provides an update from each of the five SDRC themes: Diagnosis, Fundamental Science, Informatics, Living with Dementia and Prevention. This section, authored by our SDRC Executive Committee Members, allows us to highlight recent research success and achievements encompassing all disciplines and perspectives of research, including submissions from our SDRC membership.

The second section of the SDRC Annual Report is where we will present the results from our mapping of all dementia and brain health research in Scotland from 2021, including grants awarded, papers published, and extent of collaboration with researchers outside of Scotland. We will compare this to the mapping analysis from previous years, showing trends and areas of development for research.

In the third and final section of the report, we will report on a variety of dementia and brain health related developments and good news since the last report. This includes an overview of our 2021 Conference and the launch of the first Scottish Brain Health and Dementia Research Strategy. Here, you can also find updates from some of our friends and partners at Alzheimer Scotland and Brain Health Scotland.

About the Scottish Dementia Research Consortium

The Scottish Dementia Research Consortium are a membership organisation that celebrates and supports all dementia research taking place across Scotland.

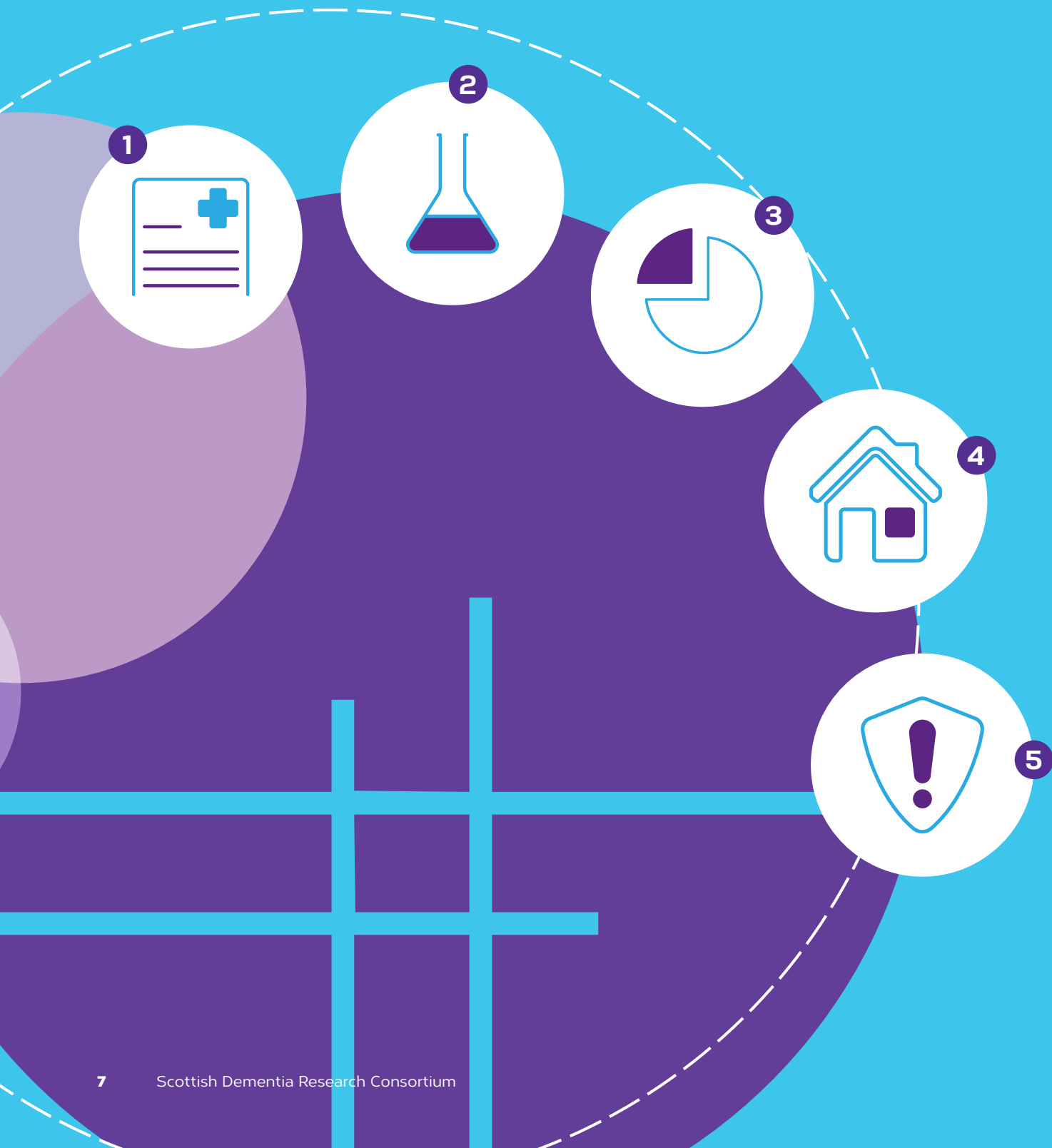
We do this by highlighting and championing ongoing work as well as nurturing growth. We also promote collaboration by encouraging researchers within and across institutions and disciplines to work together, and to help them gain a better understanding of each other's work.

The SDRC was formed in 2013 and currently has over 800 members, representing a network of researchers, policy makers and people living with dementia from across Scotland. The following are some examples of what we do for our members:

- Organising learning and networking events.
- Producing blogs featuring researchers who discuss their work and share experiences.
- Conducting our own research and producing publications which analyse the dementia and brain health research landscape in Scotland.
- Supporting researchers, particularly early career researchers, by providing personal and professional development opportunities.

SDRC membership is free and open to all. If you are not already an SDRC member, details of how to join us are at the back of this 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 — Informatics & Technologies
- 4 — Living with dementia
- 5 — Prevention



1 Diagnosis

Theme lead
Dr Terry Quinn

Twelve months is a long time in dementia research. Since our last SDRC report there have been major developments in dementia research and care. The biggest headlines have concerned new treatments, but we shouldn't forget about diagnosis and assessment. After all, the first step in managing dementia, and other memory related problems, is making an accurate diagnosis.

The diagnosis theme is focused on the evaluation of new tests and improving our use of established tests. This is the theme that 'tests the tests' and 'assesses the assessments'. Early and accurate diagnosis is a fundamental part of dementia management. If diagnosis is done well, it can help

people make sense of symptoms; can help select the right treatments and can help in planning for the future.

The diagnosis theme is not only concerned with making a diagnosis of a dementia syndrome. Tests and assessment are important at all stages of the dementia journey, from biomarkers to look for the earliest signs of brain health problems, through to assessments that help us treat and monitor those people living with advanced dementia. Within our remit is everything from technical development of new brain scan protocols through to studies of how to share a potential dementia diagnosis with a person and their family.

Work happening in theme

In the diagnosis theme, we have tended to major on new technologies such as neuroimaging and tissue biomarkers. However, applying scientific rigor and critical appraisal is just as important when thinking about established tests that are used in clinical practice. It is sometimes surprising how little robust evidence supports routine diagnostic strategies in dementia care. The diagnosis theme has played a part in raising awareness of the need for more research into clinical diagnostic pathways. Theme members have been assisting the Scottish Intercollegiate Guideline Network (SIGN) in their new dementia guidelines.¹ The guidelines are still a work in progress, but key questions on topics such as use of cognitive screening tests, remote cognitive assessment, imaging and biomarkers are all planned. In the theme we also helped give context to the recent Brain Health Scotland and Alzheimer Scotland Scoping Report looking at memory services across Scotland. With regard to diagnosis, there was substantial variation in practice around brain imaging, while biomarker and genetic testing was rarely used.² This all points to the need for research to inform guidelines and pathways.

One of the real strengths of Scottish dementia research is our track record of bringing together experts from very different areas to work in collaboration. This is especially true in diagnosis research, and the theme is proudly multi-disciplinary. One of our functions is to bring together researchers from differing backgrounds to help progress the diagnosis research agenda. We have been working with the ENRICH team (Enabling Research in Care-Homes)³ and have supported a project looking at accuracy of dementia diagnosis in care-homes. We have also had a long partnership

with the Cochrane Dementia Group⁴, and through SDRC were able to find authors for recent Cochrane reviews looking at telephone and video call based dementia assessment. As well as supporting established research teams, we also help develop new teams. For example, we helped researchers based in University of West of Scotland connect with collaborators for a project looking at post diagnostic intervention and we helped the team from University of Edinburgh access methodological advice for their paper looking at Motoric Cognitive Risk – a paper that was awarded the Royal College of Psychiatry Scotland 2021 Research Prize.⁵ Creating and supporting research networks is at the core of SDRC and we support resources such as the 'expert portal' and mentoring.⁶ Links to all of these and more are on our website, if you think we can help with your diagnosis research – please visit www.sdrc.scot/ecr-resources for more information.

In SDRC we collect data on grant income from Scottish dementia projects, and then categorise by themes. In 2021, projects related to the diagnosis theme generated over £1.5 million pounds of grant funding. This would be a substantial amount at any time, but in the context of the disruption caused by the ongoing global pandemic, this is an incredibly impressive achievement. Of course, we can't be complacent. It seems likely that the research effects of the pandemic will be felt for some time yet and we need to ensure that evidence-based, and person-centred diagnosis of dementia remains a research priority. So, for 2022 and beyond, we need to continue the tradition of innovative, high-quality, collaborative diagnosis research in Scotland.

¹ www.sign.ac.uk/our-guidelines/

² Brain Health Memory Service Scoping

³ www.nhsresearchscotland.org.uk/research-in-scotland/facilities/enrich

⁴ <https://dementia.cochrane.org/>

⁵ www.brainhealth.scot/diagnostic

⁶ <https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.12547>

⁷ www.sdrc.scot/conference

⁸ www.sdrc.scot/technologies-for-prevention-workshop



2

Fundamental Science

Theme leads
**Prof Frank Gunn-Moore
and Dr Sophie Bradley**

Fundamental science is the creation of new drugs and tests that can be used to better diagnose and treat dementia in the future. This area of research is the foundation for the development of treatments for dementia.

Scotland has a strong community of world-class fundamental scientists working in the field of neurodegenerative disease. Many of the major advances in this field, such as animal modelling, stem cell research and the MRI machine have their roots here. In addition, Scottish academic publications have highlighted major breakthroughs in much of our understanding of what we know about neurodegenerative diseases today.

The concentration of drug discovery research in Scotland is unparalleled in Europe. At present, work within the Fundamental Science theme

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. This rich understanding has led to new and world leading facilities that are aiming to translate this knowledge into potential new therapies.

Fundamental sciences in dementia research can also draw on the expertise of all Life Science researchers in Scotland, plus also 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 as an example of best practice by higher education institutions across the world and by the Scottish Government.

Work happening in theme

From Donkeys to Hippos

In the last year, there has been a continuation of expanding new areas of research now encompassing dementia and neurodegeneration research, some of them from surprising sources.

For example, two studies from the Roslin Institute and Royal (Dick) School of Veterinary Studies, epitomise such a claim with new mammalian species joining the increasing number of animals now reported to show biochemical signs akin to Alzheimer's disease. Specifically, following on from the hypothesis that animals with exceptional longevity and associated insulin metabolic issues, domestic donkeys can now be added to this list of animals. Specifically, in Malbon et al., 2022¹, the parietal lobe and hippocampus of aged (<30 years) were evaluated immunohistologically for the presence, distribution, and frequency of neurofibrillary tangles (NFT) and amyloid plaques (AP). AP were observed in the parietal cortices of aged donkeys and NFT-like structures were observed, primarily within cortical areas. In addition, there was also further signs that our feline domestic companions are also showing changes more associated in human material. In Sordo et al., 2022², 55 cats were studied and showed both intracytoplasmic and extracellular deposits of amyloid (A β), as well as intranuclear and intracytoplasmic hyperphosphorylated tau deposits, and with a similar progression of aggregates starting in cortical areas and later progress to the hippocampus.

From Strathclyde, Trevor Bushell's work on the immune system and its role in neurodegeneration comes into focus with funding coming from the ARUK which will answer the question: *Does immunomodulation promote resilience to Alzheimer's pathology?* This is based on his work of how specific receptors can influence behavioural changes through the modulation of cytokines³ and also that Interleukin-16 plays significant roles in the Central Nervous System during neuroinflammation⁴.

Also from Strathclyde, major funding for Shuzo Sakata came from his interdisciplinary research both from the MRC on Sleep regulation by neuron-astrocyte interactions (~£0.5M), but also his involvement in Horizon 2020, Research and Innovation Framework Programme, Deep brain photonic tools for cell-type specific targeting of neural diseases (~€5.7M). This is based on a series of publications from his group on brain states and Alzheimer's disease pathology, and also astrocytic calcium dynamics during the sleep-wake cycle^{5,6}.

Lastly was the developing hypothesis that a relatively newly discovered biochemical pathway (the Hippo signalling pathway) which is normally associated with the development of cancer, now has the potential to also to be involved in neurodegeneration. Holding out the possibility of yet more drug targets that could be repurposed from cancer studies⁷.

As ever, it was a year of new and sometime surprising connections.

¹ doi.org/10.1016/j.neurobiolaging.2022.01.007

² doi.org/10.1016/j.neurobiolaging.2022.01.007

³ Moudio et al. 2021; doi:10.1007/s00213-021-06040-1.

⁴ Al Dawsari et al., 2021 doi:10.3390/biology10060472

⁵ Byron et al., 2021; doi.org/10.3390/biology10080707

⁶ Tsunematsu et al., 2021; doi:10.1523/JNEUROSCI.2912-20.2021

⁷ Chen et al., 2021; doi.org/10.3390/cells10113024



3

Informatics & Technologies

Theme lead
**Prof Craig Ritchie and
 Dr Mario Parra Rodriguez**

The SDRC is witnessing a rapid expansion of Informatics and Healthcare Technologies to support dementia prevention, care and cure and to promote brain health. Such a growth has been certainly catalysed by the COVID-19 pandemic. We have decided to take a leap and expand our theme to create opportunities to celebrate and support research happening within Health Information Technologies and Healthcare Technologies. The Healthcare Technologies arm of our Theme will support research targeting the development and application of organized knowledge and skills in the form of devices, including computer-supported information systems, to tackle brain health problems and improve quality of life. The Health Information Technologies arm of the Theme aims to support research harnessing the power and possibilities of digital technologies that are able to transform data and information into knowledge¹. Scotland holds the potential be an international hub for information sciences and healthcare technologies.

In line with the aims of the Scottish Brain Health and Dementia Research Strategy, the Theme has endeavoured to increase the diversity of researchers to achieve a better representation of the relevant communities in research design, delivery, implementation and evaluation. We want to promote and encourage collaboration among different disciplines and break down silos between universities in Scotland and foster and showcase the benefits of a collegiate rather than competitive ethos. To these aims, the Theme is engaging in fruitful discussions with the Digital Health and Care Innovation Centre (DHI). By interacting with the DHI's Healthy Ageing Innovation Cluster², we have identified synergies among our efforts to deliver digital solutions for healthy ageing. We are now exploring pathways to strengthen our partnership and deliver impactful activities.

Research happening within the theme

The SDRC envisages that by leveraging the power of these research arms, more opportunities will be created to explore synergies and expand developments across them. Ongoing work supports this view. Members of the SDRC have been advancing groundbreaking research in the field of Digital Speech and Language based Biomarkers for Dementia^{3,4,5} as well as Machine Learning systems. Researchers from the Usher Institute at the University of Edinburgh are co-leading a project aimed at leveraging innovations in the use of cross-lingual embeddings coupled with deep neural networks to allow existing monolingual resources to be used across languages. The EMBEDDIA Project⁶ involves academic and industry partners interested in the development of solutions for under-represented languages and bring them to real-world contexts. The group is also interested in identifying what outcomes matter to patients with dementia and use those to aid individuals

in the pre-dementia stages. They developed the Electronic Person-Specific Outcome Measure (ePSOM)⁷ Programme which uses clustering and Natural Language Processing techniques to identify themes which matter most to individuals when developing new treatments for Alzheimer's Disease. Early Career Researchers at the University of Strathclyde have been exploring the role of social media platforms with regard to caregivers to garner their attitude towards dementia-related posts⁸. They aim to create awareness, mitigate potential misinformation, and facilitate future strategies that involve research users. Two aspects of these Health Information Technologies projects resonate with the Scottish Brain Health and Dementia Research Strategy, support to and development of Early Career Researchers⁹ and involvement of people as co-designers, co-producers and co-beneficiaries of research work¹⁰.

Within Healthcare Technologies, the SDRC recently welcomed the news about a research grant awarded by the Engineering and Physical Sciences Research Council, part of UK Research and Innovation (UKRI), to support collaborative work between the National Robotarium at Heriot-Watt University and the Applied Cognition Lab at the University of Strathclyde. Researchers at these institutions are developing AMPER, an Agent-based Memory Prosthesis to Encourage Reminiscing for people with dementia^{11,12}. AMPER will take an AI-driven, user-centred approach and will focus on personalised storytelling to help bring a patient's memories back to the surface. The partnership between the National Robotarium at Heriot-Watt University and the University of Strathclyde is also yielding timely solutions to mitigate the impact of challenges such as those imposed by the COVID-19 pandemic. The interdisciplinary group is pioneering intelligent sensing and tele-presence robotic technology to allow health practitioners to remotely assess a person's physical and cognitive health from anywhere in the world^{13,14}. At the University of Edinburgh, the Advanced Autonomy through Human-AI Collaboration¹⁵ brings together researchers from the School of Informatics of the University of Edinburgh, the University of the West of England and the University of Oxford to lay the foundations for the next generation of AI systems capable of providing new levels of autonomy in hardware and software agents^{16,17}. The collaboration aims to improve understanding of the ethical and societal implications of increased autonomy, and build a roadmap and UK community to support a future major UK initiative in this area.

To improve access to affordable technologies that can provide biomarker solutions for dementia diagnosis, the University of Strathclyde has attracted funding from the Latin American Brain Health Institute (BrainLat) to launch the first ever EEG

Global Platform for Dementia^{18,19}. BrainLat awarded a seed-grant to the Applied Cognition Lab at the University of Strathclyde to put together the EuroLAD-EEG Consortium which links six academic institutions from Europe and six from Latin American Countries²⁰.

The SDRC is aware that the above examples supporting the relevance of expanding the theme's scope and aims are just a small sample of the constellation of efforts and studies going on in Scotland. We have therefore embarked on targets that are more ambitious. We present these below.

The Scottish Dementia Informatics Partnership (SDIP) aims to link health and social care data to improve understanding of the healthcare of people living with dementia and at a high risk of developing this condition. Another component of the SDIP is the Scottish Brain Health Register (SBHR)²¹. This is a research interest register connecting people with dementia and brain health research and is situated as part of a memory clinic service. 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.

The Informatics and Technologies Theme of the SDRC is organising a workshop, that aims to deliver the Technologies for Brain Health and Dementia Prevention Special Interest Group (SIG). The SIG will attract the community actively involved in research relevant to Healthcare Technologies to explore shared interests and opportunities to join efforts. In 2022-2023, the Theme expects to increase partnerships with centres and institutions across Scotland.

Get in contact if you want to contribute to the organization of this workshop and SIG, visit www.sdrc.scot/technologies-innovation-workshop.

¹ www.who.int/teams/digital-health-and-innovation

² www.dhi-scotland.com/innovation/innovation-clusters/healthy-ageing/

³ www.frontiersin.org/research-topics/13702/alzheimers-dementia-recognition-through-spontaneous-speech

⁴ www.frontiersin.org/articles/10.3389/fcomp.2021.780169/full

⁵ www.frontiersin.org/articles/10.3389/fnagi.2021.642647/full

⁶ THE EMBEDDIA PROJECT. <http://embeddia.eu/>

⁷ <https://link.springer.com/article/10.14283/jpad.2021.30>

⁸ https://link.springer.com/chapter/10.1007/978-3-030-96960-8_20

⁹ www.sdrc.scot/covid-impact-fatima-alhayan

¹⁰ www.sdrc.scot/researchstrategy

¹¹ www.strath.ac.uk/whysthathclyde/news/2022/storytellingaitoimprovethequalityoflifeofpeoplewithdementia/

¹² www.hw.ac.uk/news/articles/2022/storytelling-ai-set-to-improve-wellbeing-of-humans.htm

¹³ www.hw.ac.uk/news/articles/2021/the-doctor-will-see-you-now-by-teleporting.htm

¹⁴ www.strath.ac.uk/whysthathclyde/news/2021/remotelyassessinghealthbyrobotsfromanywhereintheworld/

¹⁵ <https://blogs.ed.ac.uk/advanced-autonomy/>

¹⁶ <https://ieeexplore.ieee.org/document/9366406>

¹⁷ www.frontiersin.org/articles/10.3389/frobt.2021.612746/full

¹⁸ <https://iopscience.iop.org/article/10.1088/1741-2552/ac05d8>

¹⁹ www.sciencedirect.com/science/article/pii/S0167876021009399

²⁰ <https://brainlat.uai.cl/research-and-networking-projects/seed-grants/the-eurolad-eeg-consortium-towards-a-global-eeg-platform-for-dementia/>

²¹ www.sdrc.scot/sbhr-update



4

Living with dementia

Theme lead
**Prof Debbie Tolson,
 Dr Louise Ritchie &
 Dr Leah Macaden**

An important aspect of *Living with Dementia Research* is to ensure that we embrace impactful research that makes a difference to people's lives.

A lot of the work over the past year has been around developing and strengthening relationships and collaborating. In particular, we have been strengthening research connections with people with lived experience of dementia. Alzheimer Scotland's Active Voices Network, the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) have been working closely with us to strengthen research involvement and to develop involvement best practice including co-researcher models.

We are also delighted to connect with ENRICH Scotland (www.nhsresearchscotland.org.uk/research-in-scotland/facilities/enrich) which is creating a forum and infrastructure for researchers investigating care home practice and care home life. We are grateful to the Neuroprogressive and

Dementia Network (www.nrs.org.uk/dementia) for their willingness to connect applied researchers with leading NHS clinicians and practitioners. Furthermore, Connecting Communities <https://connectingcommunities.co.uk> is working with us to extend research reach in the Highlands. Such collaborations are central to dementia care and practice-based research success.

The impact of the pandemic continues to be significant on those living with dementia and subsequently, research in our theme. At the University of Dundee, SDRC member Tharin Phenwan (tphenwan001@dundee.ac.uk) has prepared a useful rapid review of internet mediated research methods with people with dementia. The paper explores practical, technical and ethical considerations (Phenwan et al 2021). Whether an experienced researcher or new to dementia research, if you are thinking about online options this is a helpful resource.

Work happening in theme

Recently Completed Work

Dr Julie Watson and the *Getting on with Life (GO)* research team from the University of Edinburgh, Durham University and Innovations in Dementia. This was a three year long project, funded by the Alzheimer's Society. They tested a seven-week online programme designed with people with dementia living in England and Scotland. It covers topics such as relationships, restoring confidence, being valued and respected by others and getting on and living your life. Findings show that GO can help participants to achieve their personal goals and live as well as their circumstances allow. It enables people with dementia to connect, share and learn from each other's unique knowledge.

Professor Kathryn Waite, Professor in Digital Marketing at Heriot Watt University, has recently completed a study funded by a British Academy/Leverhulme Small Grants Scheme. The research investigated experiences of close family members managing financial affairs of a relative with dementia. Fifty-three interviews were completed with family carers, solicitors and financial service providers. The findings contributed to the Scottish Government Fair Work Nation Consultation response.

Dr Tom Russ, Professor Heather Wilkinson, Lindsay Kinnaird, Rose Vincent, and Rosie Ashworth at the University of Edinburgh interviewed people who received a diagnosis of dementia by phone or video-call during the COVID-19 lockdown about their experience. This UKRI-funded project is being co-produced with a group of people with lived experience. They are now analysing the data and will be reporting soon. In the meantime, the project was featured in the World Alzheimer Report 2021 and the first in a series of podcasts resulting from the team has just been released, available on Spotify, Apple, and Google ("Diagnosing Dementia During COVID-19").

If you want more information about these studies, please get in touch with us and we can connect you with the relevant research teams.

Current and New Projects

Dr Rhoda MacRae with Professor Debbie Tolson, Dr James Taylor from the University of the West of Scotland, Dr Kirstin Anderson from Napier University, Dr Tom Russ and Professor Lindsay Thompson from the University of Edinburgh were funded by the Dunhill Medical Trust in June 2021 to identify and develop new effective ways to improve the health and wellbeing of the increasing numbers of older people living with dementia in prison. This project involves four Scottish prisons with the largest population of older men. The research will map the current healthcare pathways in the four establishments before by recruiting for case studies to understand dementia related experiences. The findings of this research will then be used to improve the health and wellbeing of older prisoners with dementia.

Dr Nick Jenkins, Dr Anna Jack-Waugh and Dr Louise Ritchie from the University of the West of Scotland received a Network Grant from the Royal Society of Edinburgh to develop the Multispecies Dementia International Research Network as the international forum. Established in Scotland in October 2019, the network currently consists of more than 60 academics from across the UK, Europe, and North America, working across the arts, humanities, social sciences and medical sciences <https://multispeciesdementia.org/project-members/>. This award will provide new opportunities for the network to meet, share their research and develop proposals for future research.

Dr Leah Macaden from the University of the Highlands and Islands has been awarded the Churchill Fellowship's COVID-19 Action Fund to develop and evaluate the first comprehensive dementia education resource for blended learning in care homes/home care contexts. This resource has attracted significant interest and opportunities for international collaboration.

Phenwan, T., Sixsmith, J., McSwiggan, L., & Buchanan, D. (2021). A Rapid Review of Internet Mediated Research Methods with People with Dementia: Practical, Technical and Ethical Considerations. *The Qualitative Report*, 26(11), 3318-3341. [2]. <https://doi.org/10.46743/2160-3715/20215089>



5

Prevention

Theme lead
Prof Craig Ritchie

In 2021, the Prevention theme continued to develop its strength in bringing a major output in research activity with rapid translation into clinical practice through Brain Health Scotland. In many ways this globally unique partnership working between science & research, education, clinical practice and public health policy is the reason why Scotland continues to benefit from global attention in the Brain Health and Dementia Prevention space.

This is perhaps most evident in the collaboration with the Davos Alzheimer's Collaborative and the Alzheimer's Disease Data Interoperability platform. Within DAC, we are the only country in the world to fulfil what they describe as the 'triple stack' of major involvement in their clinical trials programme, global cohort study and transformation in health care readiness (aka Brain Health Clinics).

2021 is maybe best characterised by being a development year of a higher and more robust platform to build on. These foundations have come to fruition in 2022 through the restart of EPAD Scotland, the opening of the world's first Brain Health Clinic for retired Rugby Players, the launch of a MOOC in Sports and Exercise and attainment

of major grants in the sports work from FIFA (£1.3M to University of Glasgow and £500,000 to University of Edinburgh for recruitment of retired players into the PREVENT Programme). While contact sport and dementia risk is a domain in which we are world leaders, the fact that the main population subject to traumatic brain injury is women who are subject to domestic violence or intimate partner violence means that work with this population is crucially important too. A PhD fellowship funded by the Drake Foundation to University of Glasgow marks the start of a major programme of research and clinical care in this area in partnership again with Brain Health Scotland and other stakeholder groups.

In 2022 the theme has also seen success with ongoing funding for Generation Scotland and continued academic output from the Lothian Birth Cohort. Our academic publications across this domain remain strong, influential and impactful.

Examples of our projects in prevention:

PREVENT ECO

The PREVENT Dementia programme has been working to secure funding to enable us to follow-up participants across all 5 PREVENT sites at a 3rd study visit which will be around 7 years since they first joined the study. We are pleased to share that we were successful in a recent grant application to the Alzheimer's Society and we have now secured funding for clinical and cognitive follow-up of these individuals at our sites in Edinburgh, Cambridge and Oxford. Our next step will be to secure neuroimaging funding along with funding to follow-up participants at our Dublin site.

PREVENT Rugby Football Cohort

The PREVENT dementia team are actively recruiting former elite rugby and football players eager to help shape the future of brain health in the professional sports landscape. This research is imperative to detect biological and psychological factors in mid-life that may predispose a dementia diagnosis in later life. Subsequently, we can pinpoint specific differences in this group compared to the general PREVENT cohort that could minimise the risk of dementia for sports players in the future.

For the future, we are looking at growing our capacity and delivery in Life Sciences as well as working closely with the Informatics theme to interdigitate the Scottish Brain Health Register and Join Dementia Research with Brain Health Clinics and the Electronic Medical Record. This will be a substantial and hopefully transformative piece of delivery where again research in informatics and artificial intelligence will dovetail with clinical care and research participation. Watch this space as we develop tools for decision support and trial participation.

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

This report will be the fourth time SDRC has repeated our extensive mapping of the Scottish dementia and brain health research landscape. The information featured in this mapping include awarded grants, published papers, details on our researchers based in Scotland and their international collaborators. The data that we collect includes research from all disciplines relating to dementia and brain health.

This analysis from 2021 has shown that there has been a significant increase in some areas of research activity from the previous year, specifically for grant awards. We hope that this is evidence of academia and research recovering from the impacts of the COVID-19 pandemic. We are confident that it shows that the hard work that the researchers in dementia and brain health across Scotland are putting into building their world-class reputation is being recognised.

The number of active researchers in 2021 has also increased compared to the previous five years. There remains a significant contribution from Early Career Researchers, although the number has decreased slightly since 2020. Promoting and encouraging ECR work is a key priority of the SDRC, and we will continue to support these efforts in the future.

Funding levels and sources

This section of the report focuses on grants that have been awarded to dementia and brain health researchers based in Scotland in 2021. The figures below cover grant income by year, by theme and the sources of funding including type of funding source and their location.

Number of awards: 48
Total amount of funding: £16.5 million

Figure 1: Grant income by year

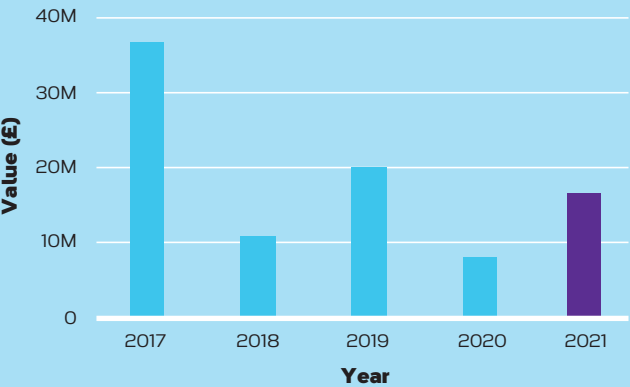


Figure 2: Grant award by theme (£)

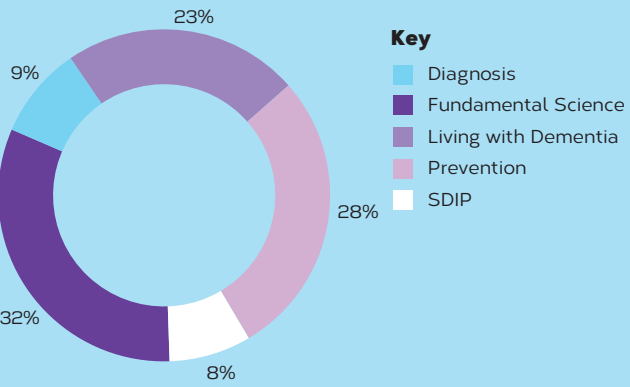
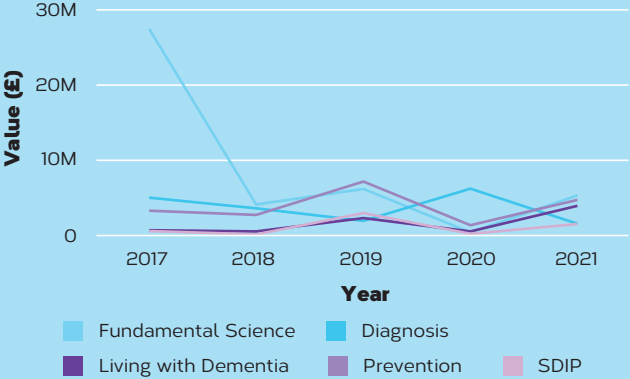


Figure 3: Grant income by year by theme



We can see from Figures 1 and 3 that there is a significant increase in grants awards from 2020. This is true for all themes except Diagnosis. However, the high amount for Diagnosis in 2020 was due to one single large award. We hope that this is evidence of investment into research recovering from the pandemic, although we will only know this for sure when we look at future investment in years to come.

Researchers in Scotland

Figure 4: Funding sources by location

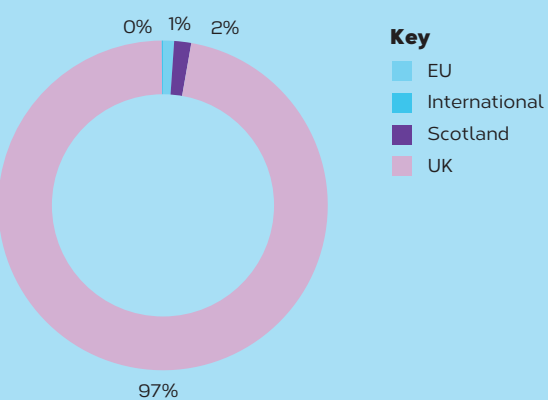
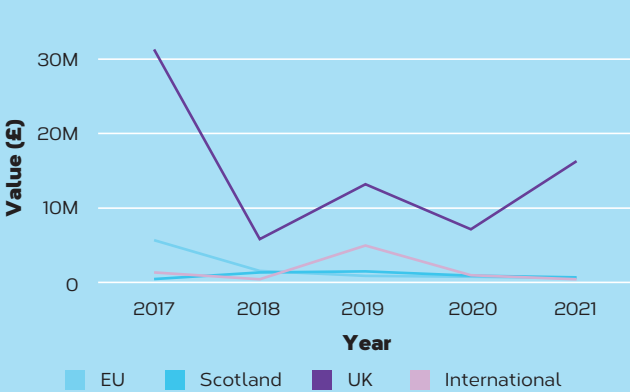


Figure 5: Funding source location by year



In 2021 there were over 500 researchers in dementia and brain health research based in Scotland. These are researchers that were either part of a successful grant award or named as an author in a published paper.

Number of active researchers in 2021: 500

Number of PhD students: 70

The following figures show a breakdown of active researchers by SDRC theme and by career stage.

Figure 6: Funding source by type of organisation

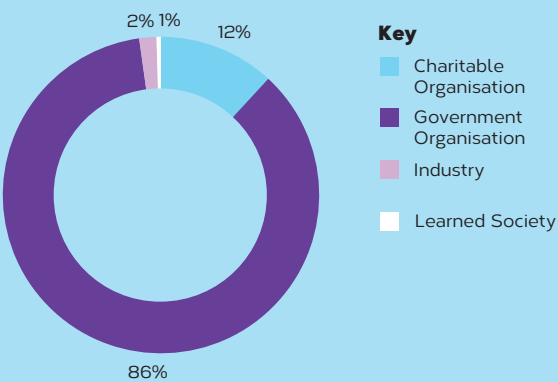


Figure 7: Funding source by organisation by year



Figures 4-7 provide more information in the source of funding into dementia research in Scotland. The location of where awarding bodies are located are shown in Figures 4 & 5 where it is clear the majority of investment comes from institutions in the UK that are not specifically Scotland. Figures 6 & 7 show the type of organisation that invest into research in Scotland. As with previous years, the majority of funding comes from Governmental organisations, for example, the Medical Research Council or the Economic and Social Research Council.

When the SDRC has spoken to various charitable organisations about research grant awards, many still were unable to commit to funding post-pandemic, however were planning on resuming this activity. We hope future reports will show an increase in the amounts of investment that charitable organisations are able to give to research.

Figure 8: Proportion of active researchers by theme

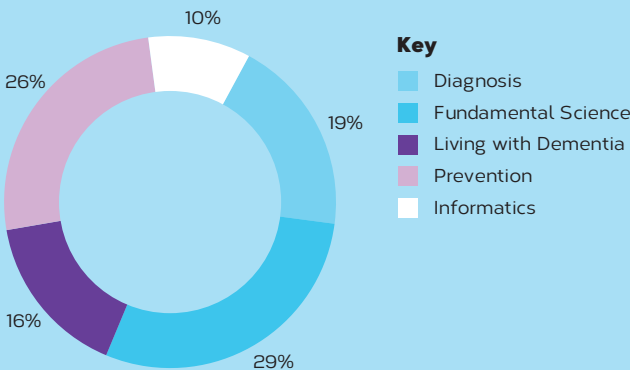


Figure 9: Researchers by career stage

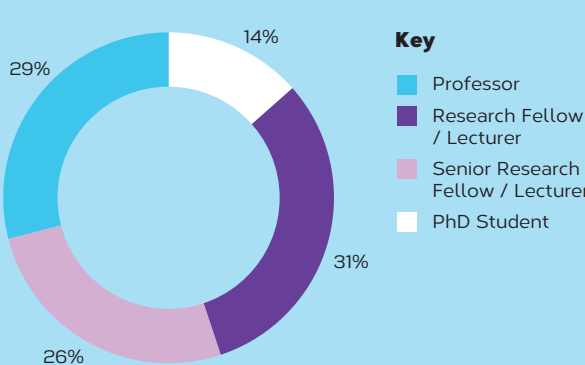
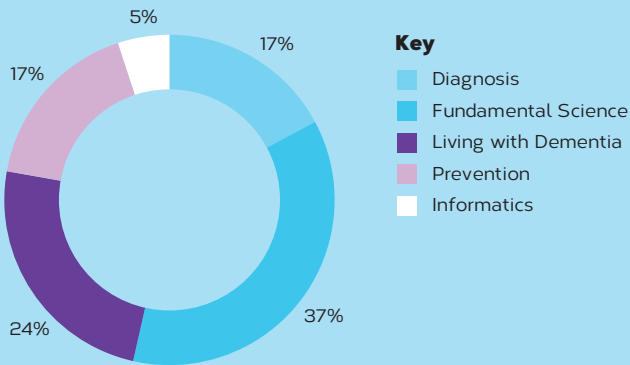


Figure 10: PhD students by theme 2020



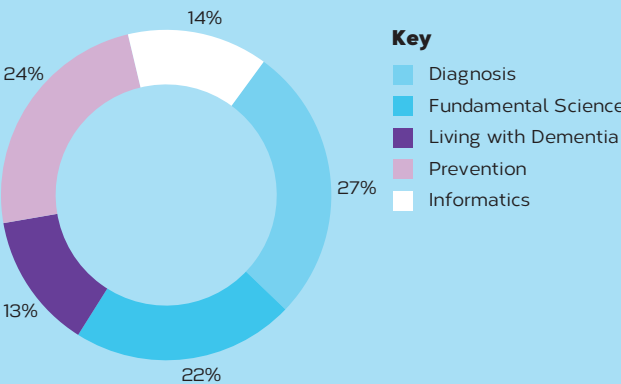
Published Papers

In this part of the research mapping, we are sharing our analysis of the number of publications Scottish based researchers had published in 2021.

Total number of papers in journals in 2021: 227

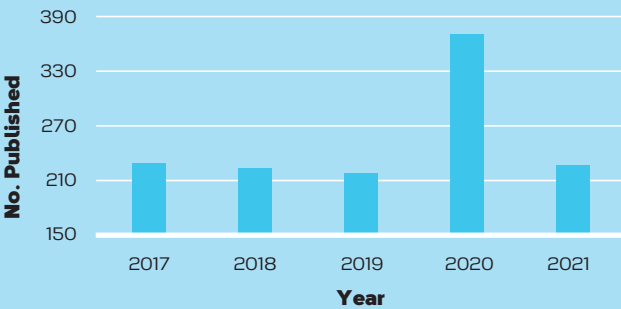
The figures below show a breakdown of papers by theme and also have compared the 2021 output to the four previous years.

Figure 11: Number of publications by theme in 2021



From Figure 12, we can see the number of papers published by researchers at Scottish institutions has fallen in line with what was seen before 2020. In the SDRC Annual Report, we did ask if the higher than usual number of papers published in 2020 was due to researchers refocusing their attention due to the reduction of grant funding available. While we cannot know for sure, the data from 2021 does suggest that published papers in 2020 was more of an anomaly as opposed to the start of a new trend.

Figure 12: Number of publications by year



International Collaborations

Here, we show the extent to which Scottish-based dementia and brain health researchers collaborate with colleagues around the world.

Number of international collaborators: 1276

Number of countries: 44

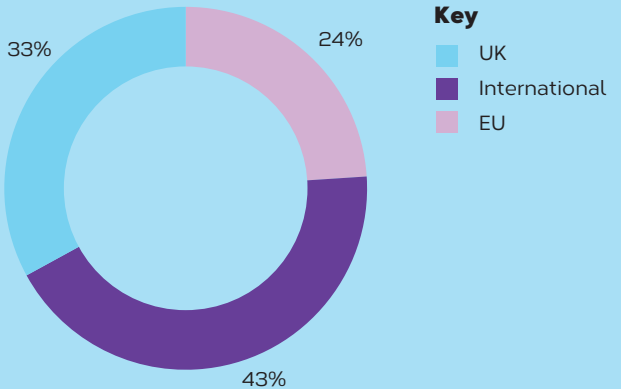
The table below shows the top 20 countries that Scottish-based researchers have collaborated with in 2021.

Figure 13: Top 20 Country Collaborations

England	410	Norway	28
USA	211	Mexico	25
Australia	86	South Korea	24
Italy	47	Belgium	19
Netherlands	47	Singapore	17
France	40	Sweden	16
Canada	39	Greece	14
China	35	Spain	14
Germany	34	India	13
Brazil	28	Chile	12

The graph below categorises international collaboration by region. This demonstrates that it is not necessary to be in close proximity to other researchers to work together with them, and to do so successfully.

Figure 14: Collaboration by Region



Alzheimer Scotland Brain Tissue Bank

The Alzheimer Scotland Brain Tissue Bank is a collaboration between the Alzheimer Scotland Dementia Research Centre at the University of Edinburgh (ASDRC) and the NHS Research Scotland Neuroprogressive and Dementia Research Network (NDN).

The Brain Tissue Bank has been operating for over a decade and has contributed to researchers' understanding of how the brain works and how it is changed by conditions that cause dementia, such as Alzheimer's disease. Much of what we know about of Alzheimer's disease, and other types of dementia, as well as advances in treatment has come through looking at brain tissue generously donated by individuals and families.

However, there is still so much researchers need to learn about how the brain changes as a person's dementia progresses. This is why the continuation of the Alzheimer Scotland Brain Tissue Bank is important, to be able to process donations of brain tissue from people with dementia after they have died, to assist with research now and in the future.

Brain tissue donation is incredibly valuable. We are hugely grateful to all the people diagnosed with dementia and their families who have supported the Alzheimer Scotland Dementia Brain Tissue Bank over the last decade and would like to encourage anyone interested in finding out more about donation to get in touch.

How to donate

Before making a decision to donate, you will be provided with information on tissue donation, the process of tissue donation, and how tissue will be used. It is vital that you feel you have sufficient information to make the important decision of whether to become a brain tissue donor after death.

To find out more about brain tissue donation, you can contact the Alzheimer Scotland 24 hour Freephone Dementia Helpline on 0808 808 3000 or visit www.alzscotdrc.ed.ac.uk

You can also register your interest via Join Dementia Research at:

www.joindementiaresearch.nihr.ac.uk

Scottish Brain Health and Dementia Research Strategy

We are all researchers

On the 8th July 2021 Alzheimer Scotland, the Scottish Dementia Research Consortium and Brain Health Scotland launched the first ever Scottish Brain Health & Dementia Research Strategy. It has been supported and endorsed by a broad range of national organisations.

It was created because the SDRC Executive Committee, alongside multiple stakeholders, recognised the importance of having a clear strategy for research. Producing, communicating and implementing high quality research is the only way to better understand the condition and how we will improve the lives of those living with the condition now and in the future.

The strategy was written to include concrete steps that can be taken to increase dementia and brain health research and sets the direction of travel in Scotland. It defines four key areas with strategic actions which are:

- To develop brain health and dementia research boards locally within NHS boards to engage with the local research agenda.
- Create a national forum which will provide a rapid research-review service in order to create a process that facilitates rapid translation of research into practice.
- Undertake a national scoping review to investigate the current situation regarding research careers in brain health and dementia in Scotland.
- Establish a national strategy oversight board to take responsibility for monitoring and supporting implementation of the strategy.

What the strategy shows more than anything is the need to collaborate with the population, as co-designers, co-producers and co-beneficiaries of research work. It means no longer considering people in research studies as 'subjects', but as partners.

Work is already underway to implement the Strategy. An Oversight Board has been established and is chaired by Former First Minister and Alzheimer Scotland ambassador Henry McLeish. We will continue to update our members on the strategy's progress in the months and years ahead through our email newsletters and social media.

You can read the full strategy at:
sdrc.scot/researchstrategy

Brain Health Scotland

Research into Cognitive Clinics in Scotland

Brain Health Scotland, an initiative hosted and supported by Alzheimer Scotland, was created with a mission to empower everyone in Scotland to protect their brain health and reduce their risk of diseases that lead to dementia.

A core commitment of Brain Health Scotland is the establishment of open access health services to support people in understanding their own risk profile and deliver personalised prevention plans.

An essential step in setting up these services is firstly to understand, in a systematic and detailed way, the current landscape of cognitive clinics across the country. Dr Jennifer Waymont, who led this important national scoping exercise describes the key findings from the project below.

For a little over a year between finishing my PhD at the University of Aberdeen and starting as a postdoc at the University of Edinburgh, I had the pleasure of working as a research officer for Brain Health Scotland. The research I was involved in had two main arms. The first was an evaluation of publicly available information via Freedom of Information (FOI) requests, NHS health board websites, and literature review. The second was a novel, nationwide survey of cognitive clinics known as The Scottish Cognitive Clinics Census 2021.

We received FOI responses from all fourteen NHS health boards. While most provided complete information, one board reported only that they take a 'person-centred' approach to evaluating cognitive complaints, and one board reported they did not provide clinical evaluation of cognitive complaints in their region. We found this information was not always corroborated by health board websites. Further, our evaluation of health board websites revealed notable differences in quantity and quality of information provided, and, in some cases, considerable difficulty in accessing/navigating to required information via the websites.

The Scottish Cognitive Clinics Census (2021) was an online census sent to Scottish services providing clinical assessment of cognitive complaints. Results revealed some similarities across services (among staff types and patient demographics) but indicated notable variation in the proportion of patients referred for further clinical investigation, among other aspects of service provision.

Findings from this work have been shared with the participating services. They have also been collated to provide recommendations from Brain Health Scotland, Alzheimer Scotland and to the Scottish Government for appropriate measures to enable more equal service provision, and more equitable access to these services across Scotland. The final report on the scoping exercise can be requested from Brain Health Scotland.

The findings of the scoping exercise, and the partnerships developed in the process, have been particularly useful in demonstrating the areas in which Brain Health Scotland's public health and clinical services can work synergistically alongside existing services for promoting brain health and preventing neurodegenerative disease in Scotland.

Expert Hub

The SDRC, alongside Brain Health Scotland, has established an Expert Hub of dementia and brain health researchers. For more than a year now, we have been in regular contact with SDRC members about the Expert Hub and how to join. Find out more below.

The Expert Hub acts as a central directory for anyone looking to connect to an expert on a specific area of brain health and dementia research (for example for a news story or input to a policy document). It should also provide a great space to display the breadth of expertise we have across our 5 themes within the SDRC.

Visitors to the expert hub will be able to filter by SDRC theme and by key search terms to generate a list of members who could be relevant to their enquiry. All incoming enquiries will come through SDRC/Brain Health Scotland first who will screen and initially respond to assess the relevance of requests. Your personal contact details won't be listed, so by joining the directory you don't need to worry about suddenly receiving spam emails.

The Expert Hub is still looking for researchers who are willing to join (this applies to researchers across all career stages). [To add your details please click this link to fill out a short form.](#) or scan the QR code below.



Feedback from the SDRC Conference 2021

The 2021 Scottish Dementia Research Consortium (SDRC) conference took place on the 16th June 2021. Due to COVID-19 restrictions, it was an entirely virtual event which was hosted by the Edinburgh International Conference Centre (EICC).

The Conference celebrated research into dementia prevention and brain health. Presenters included world-leading researchers as well as early career researchers from all disciplines.



Scottish Dementia
Research Consortium

Professor Craig Ritchie, SDRC Chair, led the event. He launched our SDRC Annual Report, and talked about the success of the research that took place over the last year. Professor Ritchie also gave a preview of the Scottish Brain Health and Dementia Research Strategy which was released in July 2021 (you can read more about that on page 20).

Our first plenary session was titled Prevention of Dementia: from observations to interventions with Professor Edo Richard from Radboud Medical Center, Netherlands. This was such an insightful presentation, and one of the many advantages of an online conference is bringing in global expertise and being able to invite international guests to present remotely.

The second part of the Conference had three breakout sessions where delegates could listen to presentations on topics of their choice, with opportunity to ask questions, contribute to discussions and share ideas. These were:

Behavioural Sciences: Explaining, Retaining and Sustaining Risk Factor Management.

Delirium and delirium prevention (dementia prevention by any other name...) a discussion about delirium, assessment, prevention and links with dementia.

Understanding Dementia: 'Class in a Bag', an important tool in helping children understand how to reduce their own risk of developing dementia and other preventable diseases in later life.

During the lunch break, our virtual conference platform allowed delegates the opportunity to network and speak with each other through meeting rooms and private chat.

Like previous years, the majority of the afternoon sessions at the conference put the spotlight on our early career researchers from all disciplines who presented their current work. These talks ranged from how technology can help people live well with dementia, risk factors in dementia and meaningful co-production in research.

The SDRC Conference 2021 closed with a presentation from Brain Health Scotland which offered insight into their core objectives and plans for the year ahead and beyond.

Message to membership

Carleen Smith, SDRC Officer

I am so pleased once again to have a chance to reflect on the past year of the work of the SDRC and also to give you a preview of what's to come in the months ahead.

Of course, we all know that 2021 was yet another year dominated by the pandemic. This brought many challenges for everyone, including the research community.

The research mapping for 2021 did indicate a significant degree of recovery after the worst of the pandemic in terms of grant funding. However, we know these figures do not tell the full story and there were a lot of research projects that were unable to continue. We will continue to support our members to get back to their research, whatever research they do and whichever discipline they are part of.

Sadly, the pandemic meant that there was a lack of in person events across the whole of 2021. I am grateful that thanks to technology, we were able to achieve so much in the delivery of online and remote events. The SDRC Conference 2021 went better than we could have expected, and feedback was overwhelmingly positive. We also held monthly webinars throughout 2021 which provided personal and professional development opportunities for researchers, focusing on early career researchers. However, in 2022, we want to get back to what we do best, which is in-person events. We have already started organising a number of workshops, which, COVID-19 restrictions allowing, I'll be able to update you on in next year's report.



One of the SDRC's greatest achievements of 2021 is the creation of the first ever Scottish Brain Health and Dementia Research Strategy (page 20). Our next step for this Strategy is putting our plans into action and we are now in the best position to do this as we start to recover from the pandemic. We have already created an Oversight Board, chaired by Alzheimer Scotland ambassador and former First Minister Henry McLeish. We will continue to update on developments and progress as it happens.

We know that the past couple of years have been tough for research, especially for Early Career Researchers. Rest assured, we are aware of these challenges, and we will do all we can to support you. In the next few weeks and months we will be updating you, as we, with the support of Alzheimer Scotland, have a number of exciting announcements.

I want to conclude this message, as I always do, with offering my sincere gratitude to all my colleagues at the SDRC Executive Committee, Alzheimer Scotland and of course the SDRC membership who make everything we do possible.

Become an SDRC member today

The SDRC is open to everyone who is taking part or is interested in dementia and brain health research.

There are many benefits to being an SDRC member. These include:

- Invitations to attend members only events to discuss dementia research
- Linking and networking with other members
- Opportunities to showcase your research and current projects to a wide audience
- Gain career advice from world leading dementia researchers

If you would like to become a member, please visit www.sdrc.scot/join



**Alzheimer
Scotland**



Scottish Dementia
Research Consortium

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Published May 2022