

# We are all researchers

Scottish Brain Health  
& Dementia Research Strategy





**Document title**  
Scottish Brain Health and Dementia Research Strategy  
We are all researchers

**Description**  
The strategy sets the direction of travel for research in brain health and dementia in Scotland by defining key areas with strategic actions. This will result in an increased national research portfolio over the strategy’s four-year lifetime (with a review after two years) that has more direct impact on the wellbeing of people at risk of, or affected by, problems with brain health or dementia. It aspires to be an empowering instrument through which practitioners, researchers and the public can come together to pursue meaningful research to help improve the lives of people with dementia and their carers.

**Commissioned by**  
Alzheimer Scotland

**Prepared by**  
Alzheimer Scotland,  
Scottish Dementia Research Consortium,  
Brain Health Scotland

**Approved by**  
Alzheimer Scotland,  
Scottish Dementia Research Consortium,  
Brain Health Scotland

**Endorsed by**  
The ALLIANCE; Allied Health Professions Federation Scotland; Association of the British Pharmaceutical Industry (Scotland); British Neuroscience Association; Chief Scientist Office; National Dementia Carers’ Action Network; NHS Education for Scotland; NHS Research Scotland; NHS Research Scotland Neuroprogressive and Dementia Network; Queen’s Nursing Institute Scotland; Royal College of Psychiatrists in Scotland; Scottish Ambulance Service; Scottish Imaging Network: A Platform for Scientific Excellence (SINAPSE); Scottish Delirium Association; Scottish Dementia Working Group; Scottish Government; Scottish Universities Life Sciences Alliance (SULSA); Stroke Association; UK Dementia Research Institute at the University of Edinburgh.

**Target audience**  
This version of the strategy primarily is for professionals who are interested or involved in research in dementia/brain health, including researchers, university leads, managers and practitioners in NHS and social care settings, policy makers and research commissioners.

**Publication date**  
8 July 2021

**Review date**  
8 July 2023

**Contact details**  
Alzheimer Scotland  
160 Dundee Street, Edinburgh EH11 1DQ  
T. 0131 243 1453  
W. <https://www.alzscot.org>

# Contents

<b>Foreword</b>	<b>4</b>
<b>Acknowledgements</b>	<b>5</b>
<b>The strategy – at a glance</b>	<b>6</b>
<b>1. Setting the context</b>	<b>7</b>
1.1 This strategy	<b>8</b>
1.2 Principles and objectives underpinning the strategy	<b>9</b>
1.3 Strategy aims	<b>10</b>
1.4 Who the strategy is for	<b>11</b>
1.5 Developing the strategy	<b>11</b>
<b>2. The strategy</b>	<b>12</b>
2.1 Developing enabling and sustainable infrastructures for research	<b>12</b>
2.2 Creating a process that facilitates rapid translation of research into practice	<b>14</b>
2.3 Promoting and resourcing researchers’ career development	<b>16</b>
<b>3. Next steps</b>	<b>18</b>
3.1 Overseeing strategy implementation	<b>18</b>
3.2 Proposed timeline and process	<b>19</b>
3.3 Resources	<b>19</b>
<b>4. Conclusion</b>	<b>20</b>
<b>References</b>	<b>21</b>
<b>Annex 1. Strategy editorial group</b>	<b>22</b>

# Foreword

**Dementia and neurodegenerative diseases continue to affect many people in Scotland, and internationally, and remain among our foremost health and social care challenges. Estimates suggest approximately 90,000 people in Scotland currently are living with dementia, two-thirds of whom are at home and one-third in acute or residential care. Around 20,000 people are diagnosed each year, with roughly the same number of people with dementia dying annually.**

The Scottish Government has been, and will continue to be, committed to improving the lives of people with dementia and their carers. Our approach continues to be to work with the people who understand dementia best – folk living with dementia, their carers, statutory, third and independent sector partners, and universities and research units – to develop policies that make a difference to the lives of those affected by dementia now and in the future.

Working with these key partners, we have been able to put in place internationally recognised initiatives to drive action in areas such as rights-based care and post-diagnostic support. We have produced three national dementia strategies to date. Since the onset of the COVID-19 pandemic, we have supported people with dementia and their carers across all care settings and, building on that work, last December we published the Dementia COVID-19 Recovery Plan, which recognises and continues to respond to the significant impact of the pandemic on people with dementia, including in the care home sector. Our ground-breaking commitment to legislate on and develop a National Care Service in this Parliament will see people with dementia and their carers as one of the key beneficiary groups.

Our commitment, and our duty, is to make life better for people with dementia now and in the future. Inclusive, participative and robust research is central to that mission. The Scottish Government was proud to work with Alzheimer Scotland to establish Brain Health Scotland. This internationally innovative centre of clinical and research expertise is leading the way in working with people with dementia and their carers, the NHS, the social care and voluntary sectors and Scotland's universities to promote positive brain health and help encourage clinical research and investment. Among its key priorities is to provide opportunities for people to join brain health research programmes in Scotland.

This first Scottish Brain Health and Dementia Research Strategy sets out an ambitious but achievable prospectus for taking brain health and dementia research to the next level by, among other actions, increasing the diversity of research participants and researchers to achieve better representation of the population of Scotland in research design, delivery, implementation and evaluation. I very warmly welcome this approach, which perfectly reflects the Government's aspiration to promote equality, diversity and inclusion across all walks of life in Scotland.

I congratulate our partners Alzheimer Scotland, the Scottish Dementia Research Consortium and Brain Health Scotland for jointly preparing this exciting new route map for research into brain health and dementia research in Scotland over the next four years and look forward very much to seeing its actions being realised in practice. Through its implementation, the strategy will ensure that people with dementia and other neurodegenerative diseases and their carers are not just beneficiaries of research, but also participants and leaders in research work.

**Kevin Stewart, MSP**  
Minister for Mental Wellbeing and Social Care, Scottish Government

# Acknowledgements

Sincere thanks to all individuals and organisations who contributed to the concept and development of the strategy and who made comments on successive drafts.

In particular, thanks go to Henry Simmons, Chief Executive of Alzheimer Scotland, for ongoing support, and to past and current members of the SDRC Executive Committee:

## Committee members 2021-present

**Professor Craig Ritchie,**  
University of Edinburgh (Chair)

**Professor Alison Murray,**  
University of Aberdeen

**Professor Debbie Tolson,**  
Alzheimer Scotland Centre  
for Policy and Practice,  
University of the West of Scotland

**Professor Frank Gunn-Moore,**  
University of St Andrews

**Dr Sophie Bradley,**  
University of Glasgow

**Dr Terry Quinn,**  
University of Glasgow

**Dr Mario Parra Rodriguez,**  
University of Strathclyde

**Dr Louise Ritchie,**  
Alzheimer Scotland Centre  
for Policy and Practice,  
University of the West of Scotland

**Dr Maggie Ellis,**  
University of St Andrews

**Dr Tom Russ,**  
University of Edinburgh

**Stina Saunders,**  
University of Edinburgh

## Committee members prior to 2021

**Professor Peter Connelly,**  
NHS Research Scotland  
Neuroprogressive and Dementia  
Network

**Professor Richard Simpson,**  
University of Stirling

**Professor Jean Manson,**  
University of Edinburgh

**Dr Karen Watchman,**  
University of Stirling

# The strategy – at a glance

## WHAT?

The Scottish Brain Health and Dementia Research Strategy sets the direction of travel for research in brain health and dementia by defining key areas with strategic actions. This will result in an expanded national research portfolio over the strategy's four-year lifetime that will have a direct and measurable impact on the wellbeing of people with or at risk of dementia and those affected by it.

## WHO?

The strategy is primarily for professionals who are interested or involved in research in brain health and dementia, including researchers, university leads, managers and practitioners in NHS and social care settings, policy makers and research commissioners.

## WHY?

The overall aim of the strategy is to create an environment in Scotland to promote the conditions for the highest quality of brain health and dementia research and the rapid implementation of research into practice.

## HOW?

The strategy aims will be delivered through four strategic actions.

**1. Brain health and dementia research boards will be developed locally within NHS boards/ integration joint boards to pursue the local research agenda in relation to dementia and brain health.** Representatives from these local boards will come together to form a national forum (hosted by Brain Health Scotland) to provide strategic oversight and sharing of local research activity in Scotland and set the direction for activity at national level.

**2. The national forum will look to provide a rapid-review service for projects conducted at local level to hasten the translation of reliable research findings into national practice and guidelines, and ensure that those that are not reliable are revised.**

**3. A national scoping review will be conducted by the Scottish Dementia Research Consortium (SDRC) to investigate the current situation regarding research careers in brain health and dementia in Scotland.**

**4. The SDRC will establish a national strategy oversight board to take responsibility for monitoring and supporting strategy implementation across Scotland.**

## WHEN?

The strategy has a four-year lifetime and will be reviewed after two years.

## WHAT NEXT?

The strategy is not an end-point, but a launch pad for a series of similar strategies focusing on discrete areas, such as fundamental science and technology and data sciences, that will be developed in due course. The focus of this initial strategy is to try and put the optimal infrastructure in place from which brain health and dementia research can further flourish in Scotland.

What the strategy shows more than anything is the need for collaboration in research work. This means not just collaboration among universities, or between them and services, or between different health professions and among them and social care services. It also means collaborating 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 and participants.

*That is why we are all researchers.*

# 1. Setting the context

Scotland has been the recipient of significant research funds for brain health and dementia research in recent years. For instance, the 2019 annual report of the **Scottish Dementia Research Consortium (SDRC)** (1), which is hosted by and works in partnership with **Alzheimer Scotland**, showed that around £160 million of research income had been granted to Scotland from various public sector organisations in the previous five years.

## What is Alzheimer Scotland?

Alzheimer Scotland is Scotland's national dementia charity. Its aim is to make sure nobody faces dementia alone by providing support and information to people with dementia, their carers and families, campaigning for their rights and funding vital dementia research. Alzheimer Scotland's activities include provision of dementia resource centres in 21 locations across Scotland, a 24-hour freephone dementia helpline and a network of dementia advisors working in local communities. It has more than 9,000 members, with 90,000 dementia friends and over 1,000 volunteers supporting its work (2).



## What is the SDRC?

The SDRC is the biggest network of brain health and dementia research in Scotland. It is a community of over 700 members who work together to bring research into practice, improve the quality of life for people with dementia and those who care for them and develop insights into the basic biology of neurodegenerative diseases. Membership of the SDRC is free and open to all, with its work prioritising the needs and aspirations of early-career researchers (3).



This kind of support enables Scotland to excel in brain health and dementia research nationally and internationally despite its relatively small size. It also imposes a responsibility on researchers in Scotland to set out a strategic vision for research activity to ensure that funding realises maximum impacts for people with dementia and their carers as well as people at risk of developing dementia. That is why Alzheimer Scotland, the SDRC and **Brain Health Scotland** have worked together to develop this strategy.

## What is Brain Health Scotland?

Developed in partnership with, and hosted by, Alzheimer Scotland and funded by the Scottish Government, Brain Health Scotland provides:

- expert advice about brain health research, policy and health care
- promotion of positive brain health in collaboration with Public Health Scotland and other partners
- support to ensure health professionals can provide individuals with personalised prevention plans through the establishment nationally of brain health services and clinics to complement existing memory clinics
- opportunities for people to join brain health research programmes in Scotland (4).





## 1.1 This strategy

While many countries have dementia plans or strategies, **Scotland will be among the first to develop a standalone research strategy for brain health and dementia. This will further enhance Scotland's status as an innovative producer of important research that leads to improvements in people's lives and enable deeper understanding of the mechanisms behind dementia and other brain diseases.**

### Why a specific strategy for Scotland?

A specific research strategy for brain health and dementia for Scotland is needed because of Scotland's devolved and integrated health and social care system and its strong traditions of collaborations among universities and research bodies. A country with devolved legislative, administrative and educational boundaries around practice needs a country-specific research strategy. In addition:

- **relevant third sector organisations (including Alzheimer Scotland) work exclusively within Scotland, as opposed to across the UK**
- **the Scottish population of around 5.3 million is large enough for research programmes to have sufficient power but small enough to be able to effectively coordinate national initiatives**
- **the Scottish Government has overseen the establishment of Brain Health Scotland, and its remit and direct influence on policy and practice is bound by national borders.**

The strategy sets the direction of travel for research in brain health and dementia by defining key areas with strategic actions. This will result in an expanded national research portfolio over the strategy's four-year lifetime (with a review after two years) that will have a direct and measurable impact on the wellbeing of people with or at risk of dementia and those affected by it.

It aspires to be an empowering instrument through which practitioners, researchers and the public can come together to pursue meaningful research to help improve the lives of people with dementia and their carers.

The strategy is not, however, a detailed action/delivery plan. It does not set prescriptive parameters for research activity. Instead, it serves as a framework from which organisations will be able to build their own action plans for delivery through the creation of brain health and dementia research boards locally and nationally. Its primary purpose is to facilitate relevant high-quality research that translates rapidly into health and social care practice as effectively as possible, and to engage more people in research activity in Scotland.

The strategy builds on the incredible strength of brain health and dementia research in Scotland (5,6). A purposeful, strategic, action-orientated approach to research will enable the achievement of greater effectiveness than would be the case if research activity was simply allowed to develop organically. It will support research activity in Scotland to engage and involve more people and promote faster implementation of research into practice.

The strategy takes its place as part of a suite of strategies and other documents that have been published in Scotland in recent years on policy, practice and research in brain health and dementia, which include:

- **Scotland's national dementia strategies (7–9)**
- **the SDRC impact report 2019 (10)**
- **SDRC annual report 2019/20 (1)**
- **SDRC annual report 2020/21 (11).**

The Scottish Brain Health and Dementia Research Strategy therefore serves to link previously published strategies and policies around service design, delivery and practice with research.

It also complements wider international work, including the EU Joint Programme – Neurodegenerative Disease Research (JPND) (12), the Davos Alzheimer's Collaborative (13) and the Innovative Medicines Initiative (IMI) Neuronet Programme (14), which are leading global research initiatives aimed at tackling the challenge of neurodegenerative diseases. The JPND explicitly stated in 2014 upon its initiation that countries should have strategic objectives for brain health and dementia research in place. Until now, none has been developed.

## 1.2 Principles and objectives underpinning the strategy

Key considerations that provided a foundation for the strategy development process include commitments to:

- **promoting equality, diversity and inclusion for everyone involved in brain health and dementia research in Scotland**
- **ensuring that research benefits society by improving health and wellbeing for individuals and communities and addressing inequalities related to dementia diagnosis, care and risk**
- **ensuring research in brain health and dementia that goes forward should, by design, have an impact across the whole of Scotland**
- **ensuring that participation in research is available to everyone irrespective of culture, gender, ethnicity or socioeconomic status**
- **supporting researchers to actively develop plans to achieve equality, inclusion and diversity in all of their research activities, including design, recruitment and dissemination of findings**
- **acknowledging that the most effective research is multidisciplinary, generalisable, equitable and accessible and meaningfully involves people living with dementia, carers and healthcare professionals throughout the research process**
- **recognising the urgent need to better understand and address barriers to career progression of dementia and brain health researchers in Scotland.**

### 1.3 Strategy aims

*The overall aim of the strategy is to:*

- create an environment in Scotland to promote the conditions for the highest quality of brain health and dementia research and the rapid implementation of research into practice.

*To support the achievement of this aim, the strategy aspires to put in place mechanisms that will help to:*

- increase the number of people with or at risk of dementia involved in research across Scotland
- ensure practice settings, practitioners and populations are educated about research, are “research ready” and are able to have “confident conversations” about research participation
- increase the diversity of research participants (by more regularly including, for example, people from marginalised groups) and researchers (through encouraging greater participation from allied health professionals and nurses) to achieve better representation of the population of Scotland in research design, delivery, implementation and evaluation
- support practitioners to be involved in research while remaining in practice settings, without the need to enter an academic setting or dedicated research-career path
- promote and encourage collaboration among different disciplines
- ensure a more coordinated approach to research in brain health and dementia in Scotland
- break down silos between universities in Scotland and foster and showcase the benefits of a collegiate rather than competitive ethos
- encourage researchers and academics to come to Scotland, and also enable those researchers who are already here to stay, by promoting and supporting research careers and providing a world-class research infrastructure
- bring research and workforce development activities together and build connections at Scottish Government level
- enable better links between policy and research by bridging the gap between science and policy
- encourage ongoing discussion on the direction of travel and identification of key challenges within the research community
- engage with the commercial sector and bodies such as Scottish Enterprise at national level
- advocate to Scottish Government, the Chief Scientist Office, funding councils and universities the need to prioritise, support and facilitate Scottish brain health and dementia research and implementation.

### 1.4 Who the strategy is for

The strategy as presented in this document is primarily for professionals who are interested or involved in research in brain health and dementia, including researchers, university leads, managers and practitioners in NHS and social care settings, policy makers and research commissioners. It is these individuals who are in a position to implement the strategic actions and drive achievement of the strategy’s aims.

An equally important audience, however, is the large group of people who will derive benefit from strategy implementation and who have key roles to play in delivering the strategy’s aims through raising research ideas and co-designing, participating in and co-evaluating the outcomes of research projects. These include people with or at risk of developing dementia, carers and the broader beneficiaries of research into brain health and dementia, such as the general public, health and social care services and local and national government.

Tailored outputs in different languages and communication formats based on this document (such as videos, social media outputs and brochures designed for the public) will also be delivered to increase accessibility and engagement, and to widen the audience for the strategy as much as possible.



### 1.5 Developing the strategy

In 2018, the SDRC Executive Committee embarked upon a scoping exercise of activity in the Scottish brain health and dementia research landscape. This culminated in 2019 in the publication of the SDRC impact report (10), which highlighted the undoubted strengths across the country. The SDRC Executive Committee nevertheless considered that these could be strengthened further through the development of a strategic, as opposed to reactive, approach, which led to the beginning of work to develop the SDRC-sponsored Scottish Brain Health and Dementia Research Strategy.

Stakeholder meetings were convened in 2019 to begin to set concrete aspirations and targets, from which the initial key areas of national infrastructure for brain health and dementia research and careers were identified. A proposal for the development of a strategy was then approved by the SDRC Executive Committee in 2020.

Drafts of the strategy were developed by a small editorial group from SDRC and Alzheimer Scotland (see Annex 1). A first draft was sent for review and opinion to the SDRC Executive Committee in April 2021, following which revisions were made and a second draft was taken forward for wider consultation with relevant stakeholders, including the Scottish Government, Royal Colleges, health and care partnerships/health boards, universities and patient/public representatives in May and early June 2021. The final draft was approved and published in July 2021.

The strategy therefore has been developed, and will be delivered, **with** people (participants, researchers and potential beneficiaries) rather than **for** people.

The strategy is not an end-point, but a launch pad for a series of similar strategies focusing on discrete areas, such as fundamental science and technology and data sciences, that will be developed in due course. The focus of this initial strategy is to try and put the optimal infrastructure in place from which brain health and dementia research can further flourish in Scotland.



## 2. The strategy

### 2.1 Developing enabling and sustainable infrastructures for research

#### 2.1.1 Rationale

**People receiving health and social care are the best agents for describing their needs, wishes, objectives and goals for the care they receive. It is these people who should be driving what improvement looks like in services. Their views, however, tend to be expressed to their families, their peer group and their carers, but not so often to researchers.**

If meaningful research is research that is driven by people’s needs as they articulate them, rather than how researchers perceive them, then it is vital that conversations take place between people and researchers.

Such conversations currently tend to occur in people’s homes and in health and care settings, so it follows that these are the locations in which research should be designed, developed and delivered. Research should be taken forward for and with the people to whom it matters most – people and their carers.

Despite efforts from bodies such as the Chief Scientist Office and research and development departments in NHS boards, relatively small numbers of people are invited to take part in research in Scotland, meaning researchers generally have contact with a small and biased number of service users (15,16). It is also the case that currently, certain communities are significantly under-represented in research, which means that their views and experiences are not included. Encouraging and supporting people from all communities in Scotland to become engaged in research must be pushed higher up the priority list of health and social care providers.

The quality improvement movement that is driving advances in the delivery of health and social care in Scotland is supported by a virtuous and ongoing cycle of clinical practice, research initiation, research participation and research implementation.

Developing enabling and sustainable infrastructures for research development, delivery and implementation **in service settings** will support greater participation in research among the people receiving and providing services and the development of research that really makes a difference to their lives. There is an artificial divide between research activity and clinical practice, created and maintained by separate “clinical” or “research” governance pathways, which amplifies an unnecessary and often inhibiting schism. This strategy seeks to remove that divide as far as possible for brain health and dementia research and practice.

#### 2.1.2 Strategic action

**Brain health and dementia research boards should be developed locally within NHS boards/integration joint boards to pursue the local research agenda in relation to dementia and brain health. Representatives from these local boards should come together to form a national forum (hosted by Brain Health Scotland) to provide strategic oversight and sharing of local research activity in Scotland and set the direction for activity at national level. It is envisaged that the first meeting of the national forum will take place in May 2022.**

The local boards would be formed of NHS and social care staff, colleagues from aligned universities, individuals and their carers and other interested parties from, for example, the third sector. They would meet regularly to discuss emerging issues from practice that reflect the views and perspectives of people and their carers and which require research input. The group would then help design, implement and evaluate the research, in partnership with relevant colleagues and stakeholders, and in alignment with the national forum. The group would also analyse and propose solutions to issues such as local barriers to research activity and encourage people and carers to come forward to be involved in research work.

## Ideas and suggestions for formation of local brain health and dementia research boards

### WHO?

The boards should be inclusive and representative of the groups who would be potential beneficiaries of research, following local and national guidance on equality, diversity and inclusion and ensuring opportunities for involvement for people from marginalised and minority communities.

This will include professionals providing and supporting care – doctors, nurses, allied health professionals, psychologists, clinical scientists, managers, administration and finance staff, social and care staff and activity officers – academics from universities, volunteers and, crucially, people with an interest in research, such as those living with dementia and their carers and representatives from the third and private sectors.

### HOW MANY?

Around 12 members is probably optimal, although extra members could be co-opted to work on any sub-groups the main group deems necessary.

### WHERE?

Spaces where members can meet comfortably and without interruption should be identified.

### WHO LEADS?

The chair or lead of the board should be appointed by the group and should not be profession-specific – it is more important that the leader should be highly motivated and have good organisational and communication abilities. The chair/lead would be the group’s representative at the national forum.

### WHEN?

The group should meet ideally on a monthly basis, and its proceedings should be minuted – these minutes would provide not only a record of decisions and actions taken, but would also be helpful in informing input to the national forum.

### WHAT?

In addition to identifying promising areas for research development, the boards would review impediments to research at local level which may be due to, for example, financial structuring and resource priorities, estates, awareness raising or staff engagement. In identifying these, they can develop action plans to remove or reduce the impediments to create more enabling environments.

Means of communication among the board but also with wider audiences in clinical, social and academic settings through electronic, paper-based and interpersonal means should be established.

One of the boards’ first tasks may be to access a register to identify people who would be interested in participating in research: the **Join Dementia Research** registration facility provides a mechanism to support boards to enable people to connect with authorised research projects and programmes.

Early consideration may have to be given to examining how the capacity of practising professionals to be involved in research can be expanded. It is suggested that each board meeting should include a review of current compliance with equality, diversity and inclusion guidance.

### What is Join Dementia Research?

The National Institute for Health Research, in partnership with Alzheimer Scotland, Alzheimer’s Research UK and the Alzheimer’s Society, has developed Join Dementia Research, a service that allows people to register their interest in participating in dementia research and be matched to suitable studies. The service delivers new opportunities for people to play their part in beating dementia and connects researchers with people who want to participate in studies (17).





2.2 Creating a process that facilitates rapid translation of research into practice



2.2.1 Rationale

Experience and analysis show that it can take a decade or more for scientific research evidence, particularly on non-pharmacological interventions, to percolate into practice. Research should go through a rigorous process of evaluation and review before it can be considered credible for implementation, but as implementation of evaluated research translating into practice during the COVID-19 pandemic shows, this process does not need to stretch over years, and can in fact be made much more rapid. Through blending research with practice, implementation and real-world evaluation can run concurrently.

This raises the question of how Scotland can take the best-quality research on brain health and dementia and ensure it makes its way through to practice rapidly. This can be done at national level through mechanisms like the Scottish Intercollegiate Guidelines Network, but it is more difficult to achieve for research conducted at local service levels.

2.2.2 Strategic action

The national forum, consisting of representatives of the brain health and dementia research boards, should look to provide a rapid-review service for projects conducted at local level to hasten the translation of reliable research findings into national practice and guidelines, and ensure that those that are not reliable are revised. Depending on the level of research expertise available to them, some brain health and dementia research boards may be able to carry out this function, or parts of it, locally.

Adopting this responsibility will enable the national forum to be aware of and to evaluate research activity conducted at local level in relation to brain health and dementia with a view to promoting safety and disseminating best practice nationally. It could lead to the building of a compendium of research activity that over time becomes established as a valuable resource for health and care practitioners across Scotland. It may also form the basis for representations to the Scottish Government for consideration in policy development.

Ideas and suggestions for national forum/local brain health and dementia research board research-review functions

The research-review function would present a conduit through which researchers at local levels could make their ideas and projects visible to a broad group of stakeholders. The board could then provide advice and facilitate the opening of doors for further research work or implementation of current findings into practice.

The normal run of events for aspiring research teams would be to present the research (whether as an idea, a proposal or a completed or semi-completed piece of work) initially to the local brain health and dementia research board for comment and to have it added to the board's portfolio. The lead of the board would submit the local portfolio to the national forum, where a register of national activity would be maintained. The national forum could then match similar activities and facilitate connections between projects to support their success and, critically, facilitate dissemination and implementation. This national register of activities will be maintained centrally on the SDRC website.

The national forum will establish communication mechanisms – emails, websites, social media and other means – to disseminate the results of approved research to other areas of the country. Brain health and dementia research board representatives on the national forum would also be able to take approved research ideas and projects back to their areas for consideration for local implementation, which may lead to the creation of collaborations involving a number of areas working on the same trials.

The national forum, the SDRC and representatives from local boards would also take the opportunity through their communication mechanisms to alert the wider health and care community of promising research taking place in other parts of the UK and internationally.





## 2.3 Promoting and resourcing researchers' career development

### 2.3.1 Rationale

It is understood that this area requires resources for salaries, laboratory costs and overheads. While it is not for the SDRC to make a business case to garner financial support for the development of researchers' careers, this strategy can set out a rationale for the advantages such support could bring.

Experience suggests that research careers in Scotland currently face bottlenecks and barriers that have been in place for some time. This is particularly, but not exclusively, the case at **principal investigator (PI)** level, which is a crucial post for achieving commissions and delivering projects. Releasing the bottlenecks and breaking down the barriers would free many aspiring researchers to access productive career opportunities and produce research that improves practice, benefits the wider community and increases research capacity in Scotland.

#### What is a principal investigator (PI)?

A principal investigator is primarily responsible for preparing, conducting and administering a research grant or other cooperative agreement in compliance with applicable laws and regulations.

Research in brain health and dementia in Scotland needs to maintain or even grow senior research leadership capacity (including PIs). This inevitably means increasing research capacity at university level, which in turn requires the creation of significant new resources. This therefore is not an aspiration that is likely to be attained in the short or medium terms.

As a first step towards the overall goal of promoting and resourcing researchers' career development, it is important to understand better the current situation regarding research careers in brain health and dementia in Scotland.

### 2.3.2 Strategic action

A national scoping review should be conducted by the SDRC to investigate the current situation regarding research careers in brain health and dementia in Scotland. This review should also look internationally for successful career pathways elsewhere in the world and analyse their applicability to the Scottish university setting.

This exercise is necessary to provide evidence from which effective interventions can be developed to promote research careers in dementia and brain health. The evidence collected from the scoping exercise will inform actions for the second brain health and dementia research strategy, which will be timed to supersede this current strategy.

The SDRC has already made substantial efforts – catalysed by the COVID-19 pandemic – to understand the needs of early career researchers (ECRs). This work will be developed further with additional resourcing and focus as part of this strategy. Ongoing improvements in ECR conditions will continue under the SDRC ECR Subcommittee established in Spring 2021 *in lieu* of the outputs from the more far-reaching review.



## Ideas and suggestions for a national scoping review to investigate the current situation regarding research careers in brain health and dementia in Scotland

*The exercise should run over the first two years of the strategy and should involve quantitative and qualitative research to establish, for instance:*

- how many PIs in Scotland are working in brain health and dementia research
- what their journey has been like to this point
- where good practice examples exist (locally and internationally)
- what bottlenecks and barriers obstruct research careers in brain health and dementia at all levels.

The research should be published through SDRC channels and act as a discussion focus to galvanise action in Scotland to promote research careers.





# 3. Next steps

## 3.1 Overseeing strategy implementation

The strategy to this point has set out three clear strategic actions that will form the foundation and infrastructure for the development of a Scotland-wide, coordinated and collaborative approach to research in brain health and dementia that is inclusive, relevant and systematic.

The strategic actions are relatively simple and straightforward, but their achievement will call for significant and coordinated effort across health and care partnerships and the academic community. The SDRC's view is that this would best be achieved by installing a board that will provide crucial oversight of implementation at national and local levels. This therefore becomes the strategy's fourth strategic action.

### 3.1.2 Strategic action

The SDRC will establish a national strategy oversight board to take responsibility for monitoring and supporting strategy implementation across Scotland.



## Ideas and suggestions for a national strategy oversight board for strategy implementation

*The national strategy oversight board may be formed of a subcommittee of the SDRC with key stakeholder membership and will be tasked with:*

- establishing a communications/outreach system through which interested parties can access further information about the strategy and its actions
- ensuring the local brain health and dementia research boards and national forum are established and are operating along the suggested lines detailed in the strategy
- ensuring the national scoping review is designed, conducted, analysed and reported according to the timeline set out by the strategy.

## 3.2 Proposed timeline and process

The COVID-19 pandemic has made setting timescales and deadlines a perilous business. At the time of writing, Scotland was in the midst of the pandemic. The country was only slowly emerging from lockdown, and the delivery of health and care services continued to be severely disrupted by the need to repurpose resources and personnel to meet the COVID challenge. The following timeline therefore may be subject to change in view of the uncertainty posed by the pandemic.

*It is anticipated that:*



## 3.3 Resources

High-quality, translatable and life-changing research comes with a cost. As the "Setting the context" chapter pointed out, Scotland has had much success in securing research commissions from a range of sources to fund brain health and dementia research in recent years. This success will need to be replicated over the four-year time-frame of the strategy and, indeed, accelerated to match the scale and ambition of the strategy's aims.

Immediate funding will be sought to kick-start the initial actions – the scoping exercise and the setting up of local and national boards. Thereafter, the boards and universities will work with Alzheimer Scotland, SDRC and Brain Health Scotland to identify ongoing sources of funding from the public, private and voluntary sectors.



# 4. Conclusion

This first strategy provides the framework to launch a coordinated and collegiate approach to brain health and dementia research in Scotland. The second strategy, due to be published in 2025, will build on this foundation by identifying specific areas for further action.

Brain health and dementia research benefits everyone in Scotland – the current and future population. To deliver the greatest advantages, it needs to engage the participation of the people who will gain most from its outcomes – people with or who are likely to develop dementia and their carers – and secure and nurture the skills and talents of those who can work with people to identify the things that are most important to them, design competent and relevant studies, conduct the research, evaluate the outcomes and disseminate their results to the benefit of all.

Scotland has a proud record in engaging the population in research work and growing talented researchers to carry projects through. But as this strategy shows, a strategic approach that provides a structured framework for brain health and dementia research production and dissemination and which further engages with all parts of the population is now required. The strategy, particularly with the creation of the local and national brain health and dementia research boards, will help to generate enthusiasm, marshal resources, extend equality, diversity and inclusion, and pool talent in an endeavour that ultimately will improve the lives of everyone participating in, and affected by, research into brain health and dementia in Scotland.

What the strategy shows more than anything is the need for collaboration in research work. This means not just collaboration among universities, or between them and services, or between different health professions and among them and social care services. It also means collaborating 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 and participants.

*That is why we are all researchers.*

# References

1. **Scottish Dementia Research Consortium.** Scottish Dementia Research Consortium annual report 2019/20. Edinburgh: Alzheimer Scotland; 2020 (<https://www.alzscot.org/news/scottish-dementia-research-consortium-annual-report-2019/20-0>).
2. **Alzheimer Scotland** [website] (<https://www.alzscot.org/>).
3. **Scottish Dementia Research Consortium** [website] (<https://www.sdrc.scot/>).
4. **Brain Health Scotland** [website] (<https://www.brainhealth.scot/>).
5. **Scottish Science Advisory Council.** Reaction to the UK Government Office for Science Foresight report “Future of an Ageing Population”. Glasgow: Scottish Science Advisory Council; 2018 (<https://www.scottishscience.org.uk/sites/default/files/article-attachments/SSAC-%20Reacting%20to%20Report%20Future%20of%20An%20Ageing%20Population.pdf>).
6. **Scottish Science Advisory Council.** Open research. How data sharing can advance scientific impact in Scotland. Glasgow: Scottish Science Advisory Council; 2019 (<https://www.scottishscience.org.uk/sites/default/files/article-attachments/SSAC%20Briefing%20Note%20-%20Open%20Research.pdf>).
7. **Scottish Government.** Scotland's national dementia strategy. Edinburgh: Scottish Government; 2010 (<http://www.wdhscp.org.uk/media/1270/dementia-strategy-2010.pdf>).
8. **Scottish Government.** Scotland's national dementia strategy 2013–2016. Edinburgh: Scottish Government; 2013 (<https://www.webarchive.org.uk/wayback/archive/20190901221358/https%3A//www2.gov.scot/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316>).
9. **Scottish Government.** Scotland's national dementia strategy: 2017–2020. Edinburgh: Scottish Government; 2017 (<https://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/>).
10. **Scottish Dementia Research Consortium.** SDRC impact report 2019. Edinburgh: Alzheimer Scotland; 2019 (<https://www.sdrc.scot/about/annual-report-2019-20/impact-report-2019>).
11. **Scottish Dementia Research Consortium.** Scottish Dementia Research Consortium annual report 2020/21. Edinburgh: Alzheimer Scotland; 2021 (<https://www.sdrc.scot/about/annual-report-2020-21>).
12. **JPND Research** [website] (<https://www.neurodegenerationresearch.eu/>).
13. **Davos Alzheimer’s Collaborative** [website] (<https://www.davosalzheimerscollaborative.org/>).
14. **Neuronet** [website] (<https://www.imi-neuronet.org/>).
15. **Darling E, Parra MA.** Involving patients and the public in research. Nurse Res. 2013 Jul;20(6):21–5. doi: 10.7748/nr2013.07.20.6.21.e341. PMID: 23909108
16. **Law E, Starr JM, Connelly PJ.** Dementia research – what do different public groups want? A survey by the Scottish Dementia Clinical Research Network. Dementia (London) 2013 Jan;12(1):23–8. doi: 10.1177/0142723711420309.
17. **Join Dementia Research** [website] (<https://www.joindementiaresearch.nihr.ac.uk/>).

# Annex 1.

## Strategy editorial group

**Professor Craig Ritchie,**  
University of Edinburgh (Chair)

**Jim Pearson,**  
Director of Policy and Research, Alzheimer Scotland

**Anna Borthwick,**  
Executive Lead, Brain Health Scotland

**Neil Fullerton,**  
Project & Communications Lead, Brain Health Scotland

**Carleen Smith,**  
SDRC Officer

**Alex Mathieson,**  
Freelance Writer and Editor

# Strategy

## endorsers





**Alzheimer Scotland**  
160 Dundee Street  
Edinburgh EH11 1DQ

**T.** 0131 243 1453  
**W.** <https://www.alzscot.org>



@alzscot | @sdrcl\_research | @brainhealthscot