Genetic Alliance UK
Supporting. Campaigning. Uniting.

Chief Scientist Office Health Research Strategy

Comments on the draft Health Research Strategy

Genetic Alliance UK, 30th September 2014

Introduction

1. Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 180 patient organisations. Our aim is to ensure that high quality services, information and support are provided to all who need them. We actively support research and innovation across the field of genetic medicine.

2. Genetic Alliance UK hosted a focus group meeting on Wednesday 17th September 2014, with clinicians and representatives from patient organisations. Discussion was led by Dr Alan McNair representing the Chief Scientist Office. Comments regarding the draft Health and Research Strategy were also invited by email, from Genetic Alliance UK's Scottish membership.

3. Genetic Alliance UK welcomes the opportunity to comment on the Chief Scientist Office draft Health and Research Strategy document.

Rare diseases and research

4. In Scotland, 300,000 (1 in 17) people are likely to be affected by a rare disease at some point in their lives. There are between 6000 and 8000 known rare conditions, 80% of which have a genetic component.[1]

5. In 2008 Genetic Alliance UK launched Rare Disease UK (RDUK), the national multi-stakeholder alliance for people with rare diseases and all who support them. RDUK successfully campaigned for a UK Strategy for Rare Diseases which was published by the Department of Health in November 2013 and ratified by England, Northern Ireland, Scotland and Wales. The Strategy represents the first time that all four UK governments have come together to produce a single comprehensive strategy to ensure people living with a rare disease have access to the best evidence-based care and treatment.

6. Within the UK Strategy for Rare Diseases, there are over 20 commitments specific to the role of research in improving the lives of those affected by rare diseases. These include:

   Commitment 22 "Support international links to UK databases and build on the work of current funded programmes that aim to link rare disease research internationally"

[1] Rare Disease UK, http://www.raredisease.org.uk/

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Commitment 29 "Improve systems to record genetic and other relevant information accurately to record the incidence and prevalence of disease and support service planning and international planning"

Commitment 35 "Use portals to connect patients and relatives to enhance research participation and, where appropriate, promote self-enrolment to approved research studies with online consenting, self-reporting and use of social media"

Commitment 43 "Evaluate different NGS platform configurations, for example:
– NGS for clinical condition-specific sets of genes (such as 100–200 of the 22,000 genes
– whole exome sequencing (2% of the entire genome)
– whole genome sequencing"

Commitment 46 "Work with industry to set priorities and determine how best to support research into rare diseases and promote research collaboration"

Commitment 47 "Support initiatives to facilitate engagement between patients, clinical care teams, researchers and industry wherever practical"

Commitment 48 "Set out the benefits of collaboration (besides producing specific treatments) for all stakeholders"

Commitment 50 "Encourage major research funders to use current structures to coordinate strategic funding initiatives in rare diseases"

Commitment 51 "Improve engagement between key stakeholders, including:
- Patients and relatives
- Main funding providers
- Healthcare commissioners
- NHS hospitals and specialist care units
- Industry (pharmaceutical, biotechnology, IT, diagnostics)"

The UK Strategy for Rare Diseases, November 2013

7. These commitments recognise the value of innovative research in addressing the high level of unmet medical need within the rare disease community and some of the barriers that currently inhibit research progress. Genetic Alliance UK speaks from the perspective of those with rare conditions who look toward innovation and research as a means to deliver effective services and new therapies for currently untreatable conditions. We believe that, on this basis, good quality, ethically sound research should be allowed to flourish.

8. During the focus group hosted by Genetic Alliance UK, many comments were raised regarding rare disease research. It was agreed that Genetic Alliance UK's response would highlight these challenges and outline the current situation regarding rare disease research:

There is limited collaboration between researchers working on rare diseases

9. The research base for rare diseases is often limited to a small number of individuals spread both nationally and internationally; and without formal networks to connect researchers, collaboration may be limited. This can result in duplication of effort, inappropriate competition for funding and overall, a lack of strategic direction. Enabling and encouraging researchers to be aware of each other's work and to work collaboratively would result in the limited funds for research into rare conditions being deployed more systematically and strategically, and would also help to draw in available collaborative expertise.

Epidemiological data and information on the natural history of many rare diseases is very limited. Patient registries can bring advantages to both research and to patient care.

10. Due to the small number of affected individuals, collecting accurate information about the prevalence, nature and expected progression or prognosis of a condition can be challenging. This information, however, is essential in making the case for funding and provides a basis for many research studies. Effective systems for data collection would also help identify patients who may wish to participate in clinical trials. Patients affected by rare diseases are generally very willing to be involved in research[2], so having improved systems in place to ensure that they are informed of ways in which they can participate would be welcomed. Support should be given to develop and sustain systems for data collection and disease registries for patients with rare diseases, including national disease registries. Public Health England (PHE) is currently working to develop a Congenital Anomaly and Rare Disease Register for England, which they expect to go live in 2017. PHE are open to collaboration with devolved nations and as such, the register may provide a framework through which Scotland can gather information on those affected by rare conditions within their own borders as part of a wider national scheme.

11. Patient registries bring advantages to both research and to patient care. Registries are used for recording prevalence and incidence, the clinical effectiveness of interventions and identifying patients for research. Registries are a key tool in the struggle to understand rare disease and a readily available list of patients makes it easier to recruit volunteers into clinical trials and research studies. The Scottish Plan for Rare Diseases "It's Not Rare to Have a Rare Disease" commits to exploring the development of an online application process and registers of interest of people with rare disease wishing to participate in relevant research. The CSO should consider supporting the development of such a registry. During the 2014 EUROPLAN UK National conference, a representative of the Scottish Government expressed an interest in collaborating with the rest of the UK in developing registries[3].

12. The Scottish Health Research Register (SHARE) is welcomed as an example of an initiative project promoting patient empowerment. Patients, and members of the public, have the opportunity to sign up to the register, share their health information and agree to be contacted by researchers. As the register relies on the coded information provided in NHS medical records to identify eligible patients, there are some concerns over the ability to match patients appropriately to the correct trials – it was noted by a delegate at the Genetic Alliance UK focus group that "medical records are only as good as the person who keeps them", highlighting the fact that many patients records are not a comprehensive resource for researchers to identify patients. The SHARE register would benefit from greater marketing, as many patient organisations reported being unaware of this facility. SHARE should be promoted by clinical staff and patients actively encouraged to join by those involved in their care.

There can be difficulties in the development of new diagnostic tests for rare diseases

13. Currently, many individuals with rare conditions do not receive a diagnosis for many years. This can cause stress and anxiety for the individual as well as prevent them from being able to access the most appropriate medicines and treatments from the earliest stage possible. With rapid progress in genetic technology, however, and notably the innovative application of Next Generation Sequencing, the speed with which new genetic tests for rare conditions can be developed should increase.

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[2] Limb et al, "Experiences of Rare Diseases: An insight from Patients and Families" (December 2010) available at: http://www.raredisease.org.uk/documents/RDUK-Family-Report.pdf

[3] RDUK, EUROPLAN UK National Conference Report (2014) available at : http://www.raredisease.org.uk/documents/europlan-report-1.pdf

Clinical trials recruitment is more challenging in the rare disease field

14. Research into rare conditions often requires recruitment of patients from multiple different sites, due to the low numbers of people affected by a particular rare condition. Barriers to local R&D approval exist because approval must be gained from the site where the research is to be undertaken and each local R&D office needs to be informed. There is no standard form between sites, requirements vary for each and no standard R&D contact listing exists. The result is often a time-consuming and challenging process that can hinder the progression of research into rare diseases either by delaying the onset of research projects, or causing termination of a project as a result of lack of available resources. An example of an initiative that has been created to improve this situation is the National Institute for Health Research UK Rare Genetic Disease Research Consortium Agreement ('Musketeer's Memorandum'); a national agreement signed up to by all host organisations for the regional genetics centres. The agreement applies to non-Clinical Trials of Investigational Medicinal Products (CTIMP) rare disease projects which have minimal local hospital costs. This ensures that when a regional genetics centre, supported by their host organisation, develops a rare disease non-CTIMP project, the local approval is applied to equivalent research in all other regional genetics centres without the requirement for further administrative work.

A lack of knowledge of rare conditions prevents the development of effective patient pathways

15. There is currently very little research on the most effective management of patients with rare conditions and management guidelines exist for very few disorders. Even specialist centres may have relatively few affected patients making the development of guidelines challenging. Funding bodies should commission research on health service delivery for patients with rare disorders, and promote and support the development of guidelines as tools to improve care management. Such research has the potential to save the NHS money and improve patient outcomes.

16. The Scottish Government launched the Scottish Plan for Rare Diseases "It's Not Rare to Have a Rare Disease" in July 2014. The plan suggests the next steps for improving rare disease research in Scotland, including actions for improving research dissemination and developing the role of genetics in rare diseases. The CSO Research Strategy should include details of the research objectives in the Scottish Plan for Rare Disease and the actions CSO will take to meet them.

Response to Consultation Questions:

Chapter 1: Efficient R&D Support for Research

Question 1: Should CSO and the Health Boards set any eligibility criteria for nodal R&D Directors? Should appointment of a nodal R&D Director be for a specific time, and if so what term would be appropriate?

- It is widely considered that the post of nodal R&D Director is essential to the success of NHS Research Scotland and it is acknowledged that those currently in post have successfully developed their roles in response to local needs.
- For the benefit of succession planning, eligibility criteria for the role should be introduced. Suggested criteria include possession of a medical degree or experience working within the NHS in Scotland, experience of raising research grant income and an understanding of the role of industry in health research. The ability to build relationships and work closely with the other nodal R&D Directors is also essential, given the necessary collaboration between the four post holders, the health board R&D staff and the CSO.
- It is recommended that the role of nodal R&D Directors would benefit from a series of Specific, Measurable, Achievable, Realistic and Time related (SMART) objectives to which the individual in post can be held accountable. This would provide the opportunity for the CSO to frame the objectives of the role, whilst allowing individuals in post a degree of flexibility in how to achieve them.
- Given the nature of this position it will take some time for an individual, new in post, to get to grips with the role and to develop it accordingly. It is important that any term imposed on the role allows the individual sufficient time to do so. Post holders should be subject to regular review against the key objectives of the post during their tenure. Posts could be advertised for a period

of five years, with the incumbent offered the opportunity to continue for longer provided they wish to do so and provided they are meeting the agreed objectives of the role.

Question 2: CSO proposes to approve the functions of staff in R&D Offices; should CSO seek to standardise local R&D functions across Scotland, or is it preferable to allow local flexibility?

- The ability of R&D offices to respond flexibly to local needs and to work within local frameworks is advantageous. However, the funds spent on R&D office staff represent a sizable investment and as such it is important to ensure there is accountability of R&D office staff. It is recommended that each member of staff have designated responsibilities and core objectives, which they are regularly evaluated against. Designation of responsibilities and core objectives will: standardise local R&D functions across Scotland, whilst affording the individuals in post the flexibility in how to achieve them, ensuring local needs can also be met; and enable clinical and research staff to identify the correct individual to approach, and increase efficiency.
- During the Genetic Alliance UK focus group it was highlighted that it can often be difficult to find the correct person within the R&D office to discuss matters with and this can lead to unnecessary delays. A website through which R&D office staff can be identified and contacted would be beneficial for all stakeholders.

Question 3: Are there other NHS Research Scotland (NRS) functions that might usefully be transferred from health boards to CSO to the new NHS Research Scotland General Manager Services (NRS-GMS)? Are there functions not currently being undertaken that the NRS-GMS might carry out?

- The introduction of the NRS-GMS is likely to absorb a great deal of the administration burden of the NRS activities which is likely to lead to greater efficiencies and a more streamlined approach.
- The NRS-GMS should also be responsible for ensuring the efficient and effective dissemination of research findings. It was noted at the Genetic Alliance UK focus group that patients and patient groups have an interest in the findings of research funded by CSO and it is often the case that this information is not freely shared. The NRS-GMS should ensure that information on research projects that are currently being funded, and the findings of research that has been funded by the CSO should be widely disseminated and publically available. This can be approached as PR activity, highlighting the role CSO is playing in delivering high quality research in Scotland and subsequently encouraging high quality research proposals and increasing opportunities for co-funding of research projects.

Question 4: To what extent should the joint planning of the deployment of infrastructure resources be formalised? Should there be a formal record of such discussions?

- It is apparent that there is a lack of understanding amongst many researchers of the level of investment in staff and researcher time that is made to support their work. Joint planning of the deployment of infrastructure resources is a sensible step to ensure there is sufficient support for research. Formalising this activity and producing a formal record of discussion is recommended and may be a valuable tool in improving the level of understanding amongst research regarding the investment in staff and researcher time, and improve organisational transparency.

Question 5: Taken together, will these steps to both free up and promote the availability of NRS resources address current concerns over lack of time and support?

- The proposed actions by CSO will lead to a more efficient and transparent process. The proposed changes must be clearly communicated to NHS staff, Health Boards and NHS researchers. The transparency offered by the proposed changes should alleviate current concerns over lack of time and support that are raised through misunderstanding of the way in which CSO funding is allocated. CSO should monitor the impact of the changes and ensure that they fully address the concerns that have been raised by NHS staff and researchers.

Question 6: Are there any further changes that should be made to improve the efficient delivery of patients to studies through the NRS Networks and Specialty Groups?

- The actions taken following the 2013 consultation have introduced a greater degree of managerial oversight to recruitment. This will increase accountability for ensuring the efficient

delivery of patients to studies. Coupled with the formalisation of the process for providing support for research through joint planning, the steps proposed by CSO will improve delivery of patients through NRS Networks and the Specialty Group. The introduction of these proposed changes must be monitored to ensure they are achieving this objective.

Chapter Two: Partnership with Scottish Patients and Public

Question 8. Would a trial register be of benefit to patients seeking trials? Would it be an effective way to partner patients with researchers? Is there a danger that expectations of taking part could be unfairly raised?

- The principle of a trial register is welcomed. A centrally held register would provide patients with a one-stop resource to access information on available studies. The register should include details of the study, what is involved and the purpose of the research. With this information, patients can decide whether the study is appropriate for them and whether they wish to take part. Appropriate filters and safeguards must be in place to ensure that the correct patients are applying for the correct trials, as there is a risk that patients may sign up to studies that are not appropriate for them. This could impose a burden on researchers to scrutinise a large number of requests and may lead to administrative inefficiencies and ultimately, disappointment of patients.
- A trial register would be a useful tool for clinicians and patient organisations. RDUK's 2012 report "Experiences of Rare Diseases: Patients and Families in Scotland"[4] highlighted that 78% of survey respondents did not feel that they were given enough information about research into their condition. A trial register would be a useful tool for clinical staff and patient organisations to provide information regarding research to their patients. It will also facilitate patient empowerment, enabling patients to actively seek research projects that may be of relevance to them.
- The public and patients must have confidence in the trial register. Information must be regularly updated, the website should include contact details for patients who wish to find out more about a study, there should be an opportunity to provide feedback on patient experiences and the website should also be used to publish the findings of studies undertaken.
- The proposal for a trial register in the draft Health Research Strategy suggests that this will be an online facility. It is acknowledged that an online, secure website would be a cost effective, accessible and maintainable resource. However, it is important to recognise that there may be many patients without access to the internet and there must be an alternative way for them to access this information. In developing a trial register, a communication strategy must also be developed.
- A trial register would be advantageous for rare disease patients if it operated on a cross border basis. It is important that any trial register includes details of research being undertaken in other parts of the UK to ensure patients with rare diseases have the opportunity to access clinical trials for their condition. An example of cross border research is the RUDY study in Oxford, which invites patients with rare diseases of the bones, joints and blood vessels from across the UK to sign up to a study which aims to transform clinical care for participants through patient driven research. The European Huntington's Disease is a further example of a successful registry which has seen 19 countries and 140 study sites participate. The registry contains details of almost 7,000 patients and families members. The registry exists to; collect natural history data of patients, relate genetic mutation with clinical symptoms, identify and recruit appropriate patients for clinical trials, plan future research studies and to develop new ways to track and predict disease onset and progression. The CSO should consider including the details of studies from across the UK and Europe on the CSO trial register.

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[4] RDUK, "Experiences of Rare Diseases: Patients and Families in Scotland" (February 2012) available at: http://www.raredisease.org.uk/documents/Research%20Report/rduk-scotland-survey-report.pdf

- There are many patient registries currently in existence. For example, each Clinical Genetics Centre in Scotland operates its own patient registry. However, each centre's registry is different and the registries are not shared across centres. In addition, many patient groups operate sophisticated patient registries. The CSO should regard support for infrastructure of registries as being equally important to supporting research trials and studies and should give consideration to supporting registries currently in existence.

Question 9. Would using electronic NHS patient records to alert GPs to research studies for which their patients may be eligible a service the NHS should offer? If so, would a process where NHS records are only accessed by identified NHS staff working in secure facilities, and only passing potential participant names to their GPs or hospital consultants for consideration, be a suitable way to proceed?

- It is agreed that offering patient's participation in clinical studies should be a key aim of the NHS as an integrated part of patient care.
- During the Genetic Alliance UK focus group, there was broad agreement that the principle of using electronic NHS patient records to alert GPs to research studies was acceptable. Concerns were raised over the sensitivity of patient records and that records can be accessed without patients consent. Stringent confidentiality rules must apply and the proposal for identified NHS staff working in secure facilities must be a minimum to ensure confidentiality and patient security is protected.
- This links into Commitment 35 within the UK Strategy for Rare Diseases which requires each nation to 'use portals to connect patients and relatives to enhance research participation'.

Chapter Three: Targeted Deployment of Resources and Infrastructure

Question 10. What proportion of CSO funding should be available for deployment in new research initiatives relevant to the NHS? In what areas should CSO seek to disinvest to free up resources?

- The policy of CSO to have flexible funds to deploy as new priorities and initiatives emerge is commended. The CSO must continue to value excellence and prioritise funding projects which are of high quality and have the greatest potential to provide health and financial benefits to patients in Scotland. It is preferable for CSO to deploy funds in the direction of initiatives which will achieve this, rather than introduce a specific quota of funding to be allocated to new research initiatives. However, CSO should undertake regular horizon scanning activities to pre-empt funding proposals for new research initiatives, allowing annual budgets to be planned accordingly.

Question 11. Is the focus of the CSO response mode grant schemes adequately defined and understood by the research community? Should there be a narrower focus to complement and avoid overlap with other funding streams Scottish researchers have access to? What is a realistic upper level for CSO grants to allow worthwhile projects to progress?

- During the Genetic Alliance UK focus group, consideration was given to whether the CSO should continue to fund entry-phase development, pilot and feasibility studies with a lower level of funding with an upper limit of £225,000 or whether the CSO should seek to raise the upper limit of funding and as a result, reduce the number of studies.
- The upper limit of funding at £225,000 is considered too low and it is recommended that this is marginally increased.
- Continuing to favour and primarily fund entry-phase development, pilot and feasibility studies is a sensible approach as there is evidence to suggest that doing so provides Scottish researchers with the evidence required to make applications to UK-wide and private funding streams. As a result, more projects are likely to be funded and undertaken than if CSO were to considerably increase the funding upper limit to fund fewer, longer term studies.

Question 12. What should determine the creation and continued funding of a CSO unit? Should any new unit have a plan for CSO funding to be time limited?

- CSO units command a considerable amount of the CSO's annual expenditure and it is understood that, with CSO designation, a unit is able to command further funding from other sources.

- It is recommended that CSO units be subject to regular review and to ensure that they are achieving the objectives set by CSO. Funding should not necessarily be time limited, but units should be regularly assessed against objectives to ensure they are providing value for money.
- Opportunities for CSO units to work in partnership may free up funding for additional CSO units. It seems that a number of the current units may share similar aims and objectives. For example the Social and Public Health Sciences Unit and the Scottish Collaboration for Public Health Research and Policy. Partnership and collaborative working between units should be incentivised and encouraged.
- Should sufficient funding become available, CSO should consider designating further units in line with Scottish Government priorities, or direct funding to specialist centres currently in existence to support research, for example the Scottish NHS Genetics Centres.

Chapter Four: Working in Collaboration

Question 13. Are there other key areas of partnership CSO should be seeking to build?

- CSO has launched successful co-funded research projects with charitable organisations in recent years. CSO should work in partnership with the Association of Medical Research Charities to identify charities with a strong research focus to continue its commitment to make working with the third sector a priority.
- Genetic Alliance UK recommends that CSO reach out to rare disease patient organisations in Scotland to identify organisations that may be developing research projects eligible for CSO funding or co-funding. Many charities supporting rare disease patients have a research focus and undertake research activities. The Scottish Plan for Rare Diseases makes a number of recommendations for encouraging research into rare diseases in Scotland; CSO should seek to identify partners to achieve the objectives set out in the Plan.
- CSO should work in partnership with Scotland's four genetic centres to identify opportunities for funding entry-phase development, pilot and feasibility studies and identifying opportunities for co-funding studies.

Question 14. Would the creation of a CSO International Advisory Board be a positive step in raising Scotland's research profile and supporting our ambition? What should be the make-up of such a Board?

- The creation of a CSO International Advisory Board would be a positive step in raising Scotland's research profile.
- CSO currently do not have partnerships in Europe or in the United States. An International Advisory Board may provide an opportunity to develop partnerships.
- An International Advisory Board would be beneficial for encouraging research into rare diseases. The research base for individual rare diseases is often limited to a small number of individuals spread both nationally and internationally. Without formal networks in place to connect researchers collaboration may be limited resulting in duplication of effort, inappropriate competition for funding and a lack of strategic direction. An International Advisory Board would be best placed to facilitate networking of rare disease researchers.
- Logistical arrangements and cost implications must be considered when developing an International Advisory Board. It is important for effective collaboration that the right individuals are involved from the beginning and that they have the opportunity to build good working relationships. Technology, such as video conferencing, could be used to facilitate regular meetings at low cost. However, face-to-face meetings are advantageous for building relationships. Utilising the Annual NRS Conference as an opportunity for the Advisory Board to meet in person may be a cost effective way to facilitate this.

Question15. Are there other areas were CSO funded research could better support the Health Directorates Quality Agenda?

- The Scottish Government's Quality Agenda requires health services to be safe, effective and patient-centered.

- CSO should ensure patients or patient representatives are involved in the CSO decision making process. The Public Engagement Group comprises lay representatives to inform CSO policy and the CSO working groups. Lay representatives should represent main disease areas, including genetic and rare diseases. Genetic Alliance UK would welcome the opportunity to participate the CSO Public Engagement Group.
- CSO should consider undertaking activities or directing funding to encouraging patient participation in research. Research represents hope for many patients and families and as such, patients and families need to be kept up to date on research developments into their condition and need to be made aware of research which may be relevant for them to participate in. Rare Disease UK's report "Experiences of Rare Diseases: Patients and Families in Scotland" found 78% of survey respondents felt that they were not given enough information about research into their condition, with many patients being forced to search for the information online. This highlights the need for more active communication about research.
- CSO should fund research looking into interventions that have the objective of improving a patient's quality of life and wellbeing. An example of such research is 'Breath Cycle' a project co-funded by the Scottish Opera and Gartnavel General Hospital Cystic Fibrosis Service to explore whether classical signing techniques could improve the wellbeing of cystic fibrosis patients.

Chapter Five: Investing in the Future

Question 16. Is the Primary Care Research Career Award scheme suitably focused to attract suitable high quality applicants? If not, what would a revised focus be?

- It is important to encourage research to be developed and carried out in the primary care setting; however the lack of interest is a cause for concern. Re-evaluating the current scheme is a sensible step, perhaps relaxing the requirements for the research to be developed and carried out in primary care – perhaps there is scope to consider projects that are developed out of the primary sector but that are carried out within it. For example, many of the patients who access the services of a geneticist have the majority of their care delivered in the primary sector. In this instance there may be scope for a study to be developed in Secondary care, but carried out within primary care.
- Should a decision be made to revise the focus of the Primary Care Research Career Awards, a suggested focus is rare disease research. An award scheme to encourage research into rare disease is Scotland would be welcomed by the rare disease community.

Question 17. Are the current CSO personal award schemes targeted to meet our future needs? If not, should CSO conduct a wider review of its capacity building schemes?

- It is important to reduce the risk of early-career academics being attracted to long-term career posts outside Scotland. The SSCF Scheme has been a welcomed initiative and has proved successful in retaining Senior Fellows within Scotland. It is recommended that such initiatives should continue and CSO should support their key partners, wherever possible, to ensure continued success of the initiatives.
- The CSO should conduct a wider review of its capacity building scheme to ensure the continuation of Personal Fellowships in Scotland meet the key needs of the research community.