Royal College of Physicians of Edinburgh
response to Chief Scientist Office on
Scottish Government Health Research Strategy

The Royal College of Physicians of Edinburgh ("the College") is pleased to respond to this consultation from the Chief Scientist's Office on the Scottish Government Health Research Strategy.

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 term, and if so what term would be appropriate?

Increasing efficiency is obviously important, and we believe the CSO and Health Board should set eligibility criteria for nodal R&D Directors. A balance is required that ensures the four regional nodes do not expand at the expense of high quality research undertaken in smaller boards/regions. It should be recognised that research is undertaken in smaller boards, including both academic and pharma sponsored multi-centre trials.

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 increase in function of staff in R&D offices may be financially expensive and must not become another layer of bureaucracy. There should be equity as well as flexibility and R&D staff must be supportive and not 'risk averse'. We welcome the proposal of having an NRS General Manager who would work at a level above those of the Health Boards and would be able to achieve coordination even in situations where there might be "political" difficulty or other conflicts.

Question 3: Are there other NRS functions that might usefully be transferred from the Health Boards or CSO to the new NRS-GMS? Are there functions not currently being undertaken that the NRS-GMS might carry out?

The management of NRS investments is an important section and we are pleased to see the requirement that Boards take adequate steps to promote availability of resources to support research.

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?

A number of Consultants wish to undertake research – could infrastructure funding be considered as sessions in a job plan? In terms of improving research and ethics, it is

important that they do function well together. Neither should be "risk averse", but research supportive. In addition, ethics must not cover issues that are covered by R&D management and vice versa. Unfortunately, this can occur at the moment.

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? If not, are there other steps NRS should take?

As stated in the consultation document, if CSO money goes into an NHS board, it should be transparently ring-fenced for research. The importance of adequately funding researchers' time is crucial to NRS/CSO resources being used to deliver clinical research effectively.

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 most frequent request from researchers to aid patient recruitment and trial delivery is the provision of research nurses. The current capacity for provision of research nurses needs strengthening and expansion. Comparison with National Institute for Health Research (NIHR) approaches is drawn to CSO attention here and we note the importance of such infrastructure to ensuring effective UK-wide clinical trials. The sharing of good practice referred to in paragraph 1.22 and elsewhere is challenging but should be pursued.

Question 7: To what extent do delays continue to occur as a consequence of differing NHS and university requirements? To what extent is closer integration of NRS and university functions possible and desirable?

There are already valuable and highly effective models where Universities and Health Boards/NHS R&D offices are aligned to provide a one stop shop for researchers. This should form the basis of best practice.

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?

Increasing patients' awareness of research and setting up a patient database is useful and important. There is a case for holding data locally at Health Board level. Most patients do not understand the need for data to be held centrally, such as in Edinburgh or Dundee, and may feel threatened by it. Here the role of patient representation can be extremely valuable.

Question 9: Would using electronic NHS patient records to alert GPS to research studies for which their patients may be eligible be 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?

Informatics is clearly important, but there may be issues of reliability. Quality and Outcomes Framework data is reliable, because it is "policed". However, there is some concern about databases, such as Scottish Care Information, where the addition of an extra zero, for instance, can give the patient duration of diabetes of 120 years, rather than 12. It is common to find patients on both oral anti-diabetic medication and insulin, when most (if not all) tablets had been withdrawn many years ago.

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

The move of profit from multi-centre pharma sponsored research to Health Boards or Universities to cover actual costs and overheads is voiced as a disincentive by research workers. This, though, is a realistic necessity with the more transparent budgeting and the move driven by government, funding bodies and Healthcare Environment Inspectorates to transparent budgeting and full economic costing. What is of more concern is that the current investment in clinical research in Scotland is running at approximately half that in England (largely via NIHR). We would welcome increased investment in clinical research and incentivisation of clinical research activity (see above) through schemes providing protected time such as NRS.

Although it is important that efficiency is improved and deployment of resources is reviewed, things that work should not be changed unnecessarily. This may lead to moving to the lowest common denominator, as often happens at Health Board level. For example, changing the present system for the Scottish Diabetes Research Network (SDRN) and subsuming it into a larger network may not be of any benefit to the SDRN.

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?

It is important that areas of research are not made too narrow. Good research can come from the unexpected. The upper level of £225,000 is difficult to adhere to, particularly if there are salaries involved. The upper level needs to be increased, possibly to £300,000 - £350,000.

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 invests in six units, which may be due to historical reasons. However, unless they can demonstrate their use, in terms of ongoing important clinical research and relevance to service provision, their roles need to be reviewed. Any new unit should be reviewed on a very regular basis. Going forward CSO units should be subjected to review every five years, perhaps fully or part-funded for one or two cycles whereafter they work towards a self-funding model. This is a very effective process through which the Medical Research Council and other major bodies deliver centres devoted to addressing major clinical research issues.

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

It is important that the medical profession is brought closer together with pure scientists. Clinicians have patients who are keen to help and pure scientists have resources which clinicians would like access to. Collaboration needs to be encouraged without competition. Partnership with the NIHR would be valued. Perhaps there a role for CSO joint funding of NIHR schemes (potentially even capitalising on NIHR infrastructure to support delivery of those investments – for example, clinical research fellowships).

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?

This would have significant resources implications.

Question 15: Are there other areas where CSO funded research could better support the Health Directorates Quality Agenda?

No comment.

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

No comment.

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?

In the past General Practitioners have been assumed to become interested in research at a similar career stage to hospital doctors. This is not the case. They are often more mature and established in practice. For this and other reasons the primary care research career award scheme is not functioning well at present. At the same time there is huge opportunity to develop meaningful research in general practice. There will be research associated with the delivery of new models of care, telemetry, Greenaway and the introduction of new models of out-of-hospital care. We are therefore keen that this scheme is reviewed to

ensure that effective community based research (the best research may not even be based in traditional general practices) is supported and developed.

Additional comments in relation to Chapter 5

Permission for audit and research can often be difficult to obtain from GPs and other sources. Patients need to be encouraged to understand that their data will be used for audit and research, rather than regarding this as intrusive and something patients need to be protected from. Informatics, which is fundamental, would be much more useful if anonymised patient data could be easily accessed.

In relation to 5.17, it is very important that evidence-based medicine is adopted. This comes with a degree of realism - if all recommendations from all the guidelines were followed (particularly from SIGN), then the Health Boards would very quickly run out of money.

All College responses are published on the College website www.rcpe.ac.uk.

Further copies of this response are available from Lesley Lockhart (tel: 0131 225 7324 ext 608 or email: l.lockhart@rcpe.ac.uk)

3 October 2014