



representing the charity sector in medical & health research

ASSOCIATION OF MEDICAL RESEARCH CHARITIES

RESPONSE TO SCOTTISH EXECUTIVE DRAFT CHARITIES AND TRUSTEE INVESTMENT (SCOTLAND) BILL

AMRC is a UK-wide umbrella organisation with over 100 member charities: a list of member organisations is attached as Appendix 1. AMRC's remit is to further the effectiveness of medical and health research charities in the UK and our comments on the Draft Bill focus on this. However, AMRC is itself a small, UK-wide charity and we have included additional comments from our perspective as an individual charity. AMRC's principal area of concern regarding the proposed regulation of charities in Scotland relates to the requirement for dual registration of a large number of charities within our sector.

AMRC members are drawn from across the UK, with only a minority operating in just one nation. Leading charities in this sector are predominantly UK-wide or British: a significant proportion also have an international remit. UK-wide and British charities aim to support the highest quality medical and health research and will support research in Scotland in competition with that of the other nations.

Medical and health research charities

AMRC members spend around £660 million per annum on medical and health research across the UK and the charity sector supports approximately one third of all public benefit medical and health research in the UK. AMRC member charities are the largest external source of funding for medical research in UK universities, including those in Scotland.

Only five charities within AMRC spend more than £10m per annum. Although some areas of voluntary activity can sustain large and nation-specific charities, this is not universally true for medical and health research areas where charities tend to be disease specific, relatively small, and with a UK-wide or British focus. This makes good sense because the nature of the disease does not change according to geographical location: diabetes and cancer are the same diseases throughout the UK. It is also the case that for most disease areas, the population of patients and supporters will not be sufficient to sustain an independent research charity in each of the four nations. **There are four charities in AMRC operating from Scotland, only two of these limit their activities to Scotland and neither of these is disease specific.**

Medical research is a global activity and is very competitive. The UK currently performs well in biosciences and funding for science, and most of the funding and regulation of science research continues to be a UK-wide responsibility of Whitehall. While there may sometimes be a unique national perspective on health delivery related research, for the most part AMRC member charities will aim to fund the best research projects wherever they occur, be that in England, Scotland, Northern Ireland or Wales. The outputs of the research are available to all in the UK, or indeed internationally. AMRC believes that the charities should aim to support only the highest quality research activity that meets their objectives and use of external independent peer review by charities is a requirement for membership of AMRC.

Charity funded research in Scotland

Over the last five years AMRC members have spent £270m in Scotland. This represents 11% of the total expenditure and compares with a population of 9%. Fundraising member charities report that the trend is for them to spend more on research in Scotland than is raised through fundraising activities in Scotland. Thus, Scotland's traditional strength in medical and scientific research means that the country is a net beneficiary of UK-wide and British charity support for medical and health research.

The Draft Bill

1. *The meaning of charity and charitable purposes.*

- a) AMRC welcomes the inclusion of the advancement of science as a specific charitable purpose.
- b) AMRC notes the inclusion of the advancement of animal welfare as an additional charitable purpose. It is our understanding that this charitable purpose would not include the furthering of 'animal rights' and that organisations established with the primary object to end animal experiments in medical research would not be encompassed by this definition. We have received assurance from the Home Office on this point and seek similar statements from the Scottish Executive.

2. *Public benefit test.*

- a) AMRC supports the proposal to remove the presumption of public benefit in some areas and the fact that in the future all charities will have to demonstrate a public benefit. AMRC has strongly supported a test of public benefit for medical research charities and supports this underlying principle.
- b) AMRC welcomes the intention that OSCR will regulate the charitable activities of Scottish universities and it is disappointment that this is not the current intention of the Home Office to do the same in England and Wales.
- c) The furtherance of education will be one of the charitable areas for which the assumption of public benefit is removed. A majority of the present charities that fund medical research do so in furtherance of an education objective and there is usually an assumption that medical research in this context is a process and is automatically for public benefit. This may not always be the case and AMRC believes that other factors, such as an emphasis on quality and dissemination, should be taken into account.
- d) Some medical research and health related charities currently aim to benefit very small populations of patients suffering from rare conditions. We have been reassured by the Charity Commission's statements that it is not intended that the numbers of beneficiaries should be a key determinant of public benefit and would emphasise the importance of this point. We seek a similar assurance from the Scottish Office.

3. *Definition of public benefit within the Bill*

- a) AMRC agrees that the list of criteria defining public benefit are helpful in understanding the nature of charities, but AMRC believes it would be wrong to seek to define public benefit within the Bill or to be overly prescriptive with regard to the way in which the regulator will be expected to apply the public benefit test.
- b) For 400 years England and Wales have benefited from a special freedom for individuals to establish organisations for public benefit that are free of interference from the State. It is largely this facility that Scotland is now aiming to enshrine in law. The definition of public benefit, and the range of organisations currently included on the Charity Commission register, has evolved over time through common law. Our members have said that this largely reflects a common sense approach, has served the public well and won broad support. **AMRC**

believes the case for changing this common law approach has not been made, and it therefore opposes most strongly the inclusion of a definition of public benefit within the Bill. It is not the intention of the Home Office to define public benefit in the legislation for England and Wales and AMRC believes a divergence of approach is likely to cause problems, particularly for those charities that operate across borders.

4. Scottish charities?

- a) AMRC finds it hard to comment on much of the draft bill because it is not clear to us which charities will be affected as there is no clear definition of what constitutes a 'Scottish' charity. The terminology, 'operating in Scotland' seems to be deliberately vague. The consultation document tends towards a distinction between a charity registered in Scotland and a Scottish charity, but this is by no means consistent. More recent briefing has made reference to organisations that wish to call themselves a charity in their Scottish activities.
- b) There appears to have been a disappointing lack of forethought given to the role UK-wide and British charities play within the voluntary sector in Scotland. The consultation paper does not cover the potential wider impact of the proposals beyond the right of the public in Scotland to know that charities 'operating in Scotland' are subject to Scots Law and on this basis dual registration and regulation is justified. The possibility of the proposals having a negative impact is not considered.
- c) In her introduction to the consultation, Margaret Curran refers only to Scotland's charities and the generosity of the Scottish public. The consultation generally looks at regulation on the basis of 20,000 'Scottish' charities and yet the preliminary index already lists a number of organisations based in England or 'further afield' with a UK-wide or international remit. This lack of definition regarding what charities will be included on the Scottish register is fundamental. Until there is greater clarity a sensible consultation on the impact of the proposed regulation cannot possibly take place.
- d) AMRC understands that the Scottish Executive has not completed its impact assessment of the proposed regulation and that no analysis of how many British, UK-wide charities, and 'further afield' charities already registered or recognised elsewhere, will be affected by a broad interpretation of 'operating in Scotland'. This is disappointing, given that there appears to be no intention to consult further on the Bill before its introduction in the Scottish Parliament.
- e) Because of this confusion and a growing concern amongst those AMRC has consulted, AMRC has sought clarification from the Scottish Executive and OSCR regarding the definition of 'charities operating in Scotland'. **We have now been advised that it is the Scottish Executive's intention to register in Scotland any organisation that fulfils its charitable objects in Scotland or claims to have beneficiaries in Scotland.** Charities that wish to use the term 'charity' in their activities in Scotland will also need to register.
- f) AMRC believes that this will require duplicate registration in Scotland for many more organisations than most of us had envisaged originally. Excluding issues relating specifically to fundraising in Scotland, some examples would be:
 - All charities that give grants in Scotland (but presumably not overseas - further afield? - grant givers);
 - UK- wide or British organisations representing professionals
 - International, UK- wide or British campaign groups
 - Any charity that funded a public or scientific meeting in Scotland, or a public event for example at the Edinburgh Fringe or the Shetland or Edinburgh Science Festival;
 - Patient groups that produce information leaflets available to people in Scotland or with a web site that gave advice on NHS treatments;
 - Groups providing telephone helplines or counselling services available to people in Scotland;
 - All UK- wide or British umbrella organisations

- g) UK-wide and British charities are unlikely to reproduce materials especially for use in Scotland unless there is a justifiable reason for them to do so. Using AMRC as an example, it is hard to envisage a situation in which AMRC would use the term 'charity' in Scotland differently from the way it will use the term 'charity' for its activities for the UK as a whole. AMRC would not intend to produce a different letter head or leaflets for circulation in Scotland and it would assume that the Scots would access the England based web site or telephone advice without staff needing to make clear that AMRC was not separately registered as a charity in Scotland. It is difficult to see how the public, or OSCR, will be able to distinguish the term charity in different geographical locations unless it took steps to preclude un-registered charities from responding to Scottish enquiries or circulating information to Scotland.
- h) AMRC therefore believes that the suggested definition of charities operating in Scotland is now far too broad and will require a large number of externally based organisations to have dual registration. This could create a disincentive UK-wide or British charities to work in Scotland thereby causing a disadvantage to the public in Scotland.
- i) AMRC suggests that the definition of a charity 'operating in Scotland' should focus on the degree to which the organisation has a 'Scottish' identity or presence, is referred to as a Scottish charity, or fundraises on a regular basis in Scotland.

5. *Minimising duplication and bureaucracy*

- a) The commitment in the consultation to minimise duplication and keep regulation proportional sounds rather hollow given the present intention to insist on dual registration for so many different types of organisations. The Scottish Executive appears determined to take a different path on many areas of charity regulation, possibly even at the basic level of the definition of public benefit. This approach ignores growing trends across Europe to accept regulation in one member state as adequate. The tone of the Scottish Executive paper is that UK-wide and British charities must accept this as a matter of fact.
- b) Although the Scottish Executive states an intention to share information and data across borders with the Charity Commission, at the same time it is quite clear that the proposals for this regulatory model in Scotland will demand duplication and considerable additional information. For example, OSCR will regulate only the portion of activities undertaken in Scotland (with no commitment to consistency with England and Wales); yet current data and information required by the Charity Commission does not seek separate detail on income derived from Scottish sources, expenditure on beneficiaries in Scotland or specific analysis of activities by nation. Without this information it is hard to see how OSCR will be able to identify the Scottish activity it intends to regulate.
- c) AMRC welcomes the stated commitment to minimise the bureaucratic burden for charities. The resources for any regulation should be justified in terms of gains to both the regulator and the regulated and OSCR should make every effort not to increase the administrative burden on charities or to increase their administrative costs.
- d) The smaller charities within AMRC have no paid staff and many others have only one or two staff covering all areas of activity from patient support, fundraising and research administration. Where charities have established fundraising activities in Scotland, or perhaps branches, the indications are that if they must, they will live with the additional burden of dual registration and duplicate reporting. But for those charities that support activities only occasionally in Scotland, the early indications are that they will no longer operate north of the border. It is quite possible to foresee a situation where a medical research funder is dissuaded from making an award to a Scottish institution because to do so will require them to register as a charity in Scotland.
- e) **AMRC believes that where an organisation is accepted on the register in one country this registration should be automatically accepted across the UK. AMRC would**

encourage OSCR and the Charity Commission to work together to develop practical and non-bureaucratic proposals for the identification and provision of information on charities registered in one nation but whose remit covers more than one nation.

6. *Medical and health research – the UK wide perspective*

- a) It is important that charitable resources for medical research support the highest quality and most relevant research possible in the field, and, as a principle of good practice, funding should support the best research wherever in the UK it may occur.
- b) At present, there is very little charitable research funding ring-fenced for Scotland and Scotland performs well in a UK wide environment. Where smaller local research funds exist the quality of the research supported may be called into question because it may not be competitively assessed. AMRC understands that the Scottish Executive has no data on charitable funders of medical research in Scotland and has not assessed the potential impact of the regulation for this area of activity. Examination of the preliminary list of charities in Scotland identifies a little of 5% as health related: we believe that this grossly underestimates charitably funded medical research activity in Scotland and AMRC recommends that the Charity Bill team enter into discussions with the Chief Scientist.
- c) Research is increasingly both interdisciplinary and collaborative between institutions. Because of Scotland's historic strengths in medical research, many English based organisations support collaborative research across the border with Scotland even though they might not themselves be Scottish charities. To insist on a second registration may be a disincentive for such organisations to continue to support such collaborations.
- d) It will be important for the charitable support of medical science and health research that there is consistent interpretation of charity law. In the absence of an authority in Scotland, the Charity Commission has led this work in the UK and at present there is a level of consistency in interpretation. But the consultation and Scottish proposals have already moved towards some de-coupling in interpretation of public benefit which may in due course have an impact on the interpretation of the boundaries of what is or is not charitable research. AMRC believes the two regulators should make a commitment to achieve consistency in the interpretation of the law wherever possible.

7. *UK-wide umbrella organisations*

- a) AMRC, like many sub-sectoral umbrella bodies, has a UK-wide remit. AMRC would claim to be delivering a public benefit across the UK: the indications are that this makes us a 'charity operating in Scotland'. Organisations like AMRC have an increasing role within the charity sector as the focus on quality and performance, accountability and effectiveness grows.
- b) Our stakeholder communities, from patients to researchers, are clear in their desire that standards in medical research grant making should be UK-wide. This position is reflected in AMRC's approach to all medical and health research policy issues.
- c) In terms of the integrity of the research that charities fund, AMRC believes that the public would also expect the same standards to apply across the UK. We believe that any fragmentation will diminish public confidence in medical research.
- d) The major part of science funding for the UK remains the responsibility of Whitehall, as does the regulation of important areas of research such as the use of animals. It is essential therefore that AMRC maintains its focus on UK-wide representation of the sector's interests.
- e) Like many specialist umbrella groups, AMRC is a small organisation with an annual expenditure of around £450,000. We do not fundraise in Scotland but we provide briefing and support for all our members on an equal basis regardless of where in the UK they are based.
- f) AMRC organises the occasional meeting in Scotland, for example at a science festival,

training for trustees, or for researchers seeking funding. Where there are differences between the four nations in areas that impact on medical research, AMRC will work with the relevant authority but our key aim is to maintain consistency across the UK. To require organisations like AMRC to have an additional registration in Scotland will add to our bureaucratic burden and duplicate much of the information already returned to the Charity Commission in England and Wales.

- g) We note that there is no reciprocal intention by the Home Office for dual registration of charities based in Scotland that may deliver their charitable objects in England and Wales. Under the current Scottish Executive proposals, the only way to avoid duplicate registration would be for all UK-wide or British charities to swap their Charity Commission registration for OSCR in Scotland!
- h) AMRC notes also that for those charities that are also limited companies, there will be no requirement for them to register separately as companies in Scotland in order to be able to operate in Scotland. There does therefore seem to be an inconsistency in the approach for charities.

25th August 2004