

Best Research for Best Health: A New National Health Research Strategy

Consultation Questions

Closing Date: 21st October 2005

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This questionnaire is to be completed based on the consultation document at <http://www.dh.gov.uk/Consultations/LiveConsultations/>. Please email the completed document to RDconsultation@dh.gsi.gov.uk. For any queries or information, please contact this email address or telephone 020 7972 4113.

Are you responding as a) an individual, or b) on behalf of an organisation? Organisation	ORG
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Question 1- Challenges

a	Are these the main challenges? YES/NO	YES - SOME
b	Are there other important challenges that we need to take account of?	
<p>These are some of the main challenges but others could be added. These include the legislative framework, notably the Data Protection Act and the EU Clinical Trials Directive, both of which appear to have been “gold plated” within the UK (compared with other EU countries) and have contributed to many of the difficulties encountered in undertaking research. The Human Tissue Act could also be included in this list.</p> <p>Although the figure identifies NHS Trust management as the main bureaucratic block to research there are other sources, including the lack of guidance from the “centre” about such matters as mutual recognition of CRB checks on researchers between NHS bodies and the vagueness of key elements of the research governance framework. COREC and its regional officers have made some valuable progress with respect to the working of</p>		

Research Ethics Committee.

Another matter that could be mentioned is the continuing lack of mutual understanding between some NHS bodies and universities about the common purpose underlying health research and the benefits to both parties. Research is also frequently hampered by disagreements over coverage of Excess Treatment Costs as well as Support for Science costs and indemnity arrangements (especially in primary care, and particularly where individual RECs have a predisposition to favour no-fault cover).

Although the figure identifies that NHS R&D funding is allocated on an historical basis it was of course the result of the Culyer declaration in 1996 which was supposedly based on “real” activity levels. The demands of performance management around clinical work have also inhibited enthusiasm for research among some senior managers. The fact that 40% of clinical academics are funded by the NHS is not in itself necessarily a problem. More problematic arguably is the lack of career structure and protected research time for nurses and allied health professionals wishing to undertake research

Finally, although the consultation notes the importance of primary prevention and early detection, the issues laid out do not take account of some of the differences between clinical and public health research. By implication, it assumes that changes that will enhance clinical research will also enhance public health research. This assumption should be examined

Question 2 - Building Blocks

a	Are these the main building blocks that we (Department of Health/National Health Service) have at our disposal? YES/NO	YES
b	Are there other important elements that we need to consider?	
<p>We would agree that these constitute the main existing funding streams emanating from the NHS. Contextually the substantial HEFCE funding in support of health related research could also be mentioned as the success of UK health research is built upon a strong partnership between NHS and universities. The drug industry and charities also contribute in an important way to capacity development through funding of fellowship posts (or similar).</p>		

Question 3 - National Institute for Health Research

a	Will the creation of a virtual National Institute for Health Research achieve the objectives of creating coherence and focus for the different strands of our work? YES/NO	NO
b	Would another mechanism work better? YES/NO	YES
c	If so, what?	
<p>The biggest problem with the proposed NIHR is its coverage. As the strategy indicates, only 40% or so of clinical academics – never mind non-clinical health researchers – are employed using NHS resource. The remainder are omitted from this virtual organisation with the attendant risk of fragmentation rather than coherence. We would much prefer to see some way in which HEFCE and other funded clinical and non clinical academics could be associated with and gain some of the benefits of involvement in the NIHR.</p>		
d	Does the name National Institute for Health Research appropriately describe its role? YES/NO	YES

Question 4 - National Institute for Health Research Faculty

a	Do you agree that we should create a staff structure which ensures proper support for all those engaged in research for the benefit of patients? YES/NO	YES – with emphasis upon ALL, regardless of funding
b	Do you agree with the concept of a National Institute for Health Research faculty? YES/NO	YES
c	If no to a and/or b above, what mechanism(s) should be used to ensure these staff are supported?	
	The problem is of creating a fragmented system in which only some are members of the NIHR. If this can be overcome then the NIHR should be supported	
d	Do you agree with the three groupings (Senior Investigator, Faculty Associate, and Junior Investigator) as proposed? YES/NO	YES
e	If not, what groupings would you use?	
f	Do the names Senior Investigator, Faculty Associate, and Junior Investigator appropriately describe the different groups? YES/NO	YES
g	If not, what names would describe them better?	
h	Is it appropriate to include the NHS-funded staff in universities? YES/NO	YES - as long as those with other funding are also included

i	Should the funding for these staff be held centrally to ensure protection of research time? YES/NO	UNCERTAIN
<p>Centralisation of the NHS funding – in essence a Culyer-type claw back and then reimbursement – has certain advantages in that it permits continuity but it also places control of a potentially large body of academics in the hands of a central body. Will that body be able to cope with the opportunities and changes in the system?</p>		
j	What would appropriate ‘allowances’ be for the three groups of faculty staff?	
<p>Appropriate allowances would be £5K, £2K and £2K per yr respectively for senior, associates and junior</p>		

Question 5 – Infrastructure (i)

a	Are the proposals for Support for Patient Research appropriate? YES/NO	NO
b	If not, what would achieve the aims better?	
<p>The Support For Science changes are defensible in one sense – and could lead to a much fairer allocation in principle. However they could lead to instability especially for Trusts with small to medium levels of activity who could see sizable proportional fluctuations in their income from year to year depending on small numbers of projects. Better arguably to have a baseline stable allocation which is then modulated according to the actual projects undertaken.</p> <p>Some further work needs to be undertaken as patient numbers alone will not be a sensitive measure and will be too simplistic a metric, especially for complex research with vulnerable populations, public health research and other research that is relevant to the NHS but does not directly involve patients.</p>		

Question 6– Infrastructure (ii)

a	Are the proposals for Academic Medical Centres appropriate? YES/NO	NO
b	If not, what would achieve the aims better?	
<p>The aims of a number of centres of excellence is not to be dismissed immediately – the Manchester based National Centre in Primary Care has been a beneficial influence in primary care. However the key questions and areas of concern are twofold. How will the £100M funding be found? And will it be stripped out of existing settings? And second will the Centres genuinely concentrate upon research of clear NHS interest or will they be sucked into blue skies “research council” research? The devil is in the detail of what is meant by translational research and upon which part of the research spectrum attention will be focussed? Third – how will this impact upon the ambition to distribute research interest and activity widely through the NHS? There is a clear risk that in concentrating in this way the breadth of engagement will be lost</p> <p>Arguably it would be better to establish a smaller number (say 2/3) of pilot centres to see how they flourish or whether they develop into blue skies centres with little NHS linkage.</p>		
c	Should we support both comprehensive centres and specialist centres? YES/NO	YES
d	How many of each can we support if they are to be truly world-class as the exemplars?	1-2 of each
e	What time period should be awarded before a new competition round?	3-5 yrs

Question 7 – Infrastructure (iii)

a	Are the proposals for Leadership Funding appropriate? YES/NO	YES
b	If not, what would achieve the aims better?	

Question 8 – Infrastructure (iv)

a	Are the proposals for Technology Platforms appropriate? YES/NO	UNCERTAIN
b	If not, what would achieve the aims better?	
<p>In principle this proposal is reasonable but we must be careful that there is sensible geographical coverage so that there are not locations which are deprived of access to these expensive technologies by virtue of their distance from the relevant facility.</p>		
c	What should be the first area(s) for focused support?	
<p>The first area for focussed support should be bioinformatics expertise – which is just as much a platform technology as genomics and is also underprovided.</p>		

Question 9 – Infrastructure (v)

a	Are the proposals for Experimental Medicine appropriate? YES/NO	YES
b	If not, what would achieve the aims better?	

Question 10 – Infrastructure (vi)

a	Are the proposed infrastructure elements to create optimum systems the right ones? YES/NO	YES
b	Are there other potential elements that we should consider? YES/NO	YES
<p>The notion of academic medical centres acting as a support structure to UKCRC is not without merit. However it is important that there is supported research initiation capacity at the ends of the “spokes” as well as within the “hubs”. Smaller academic centres should not be stripped of resource and capacity to initiate research, in the interests of boosting the Academic Medical Centres</p>		
c	What should the balance of investment between the different infrastructure elements be? (i.e. what should be the percentage spend on each?)	
<p>It is not clear what the different infrastructure elements intended to be considered actually are. However if we suggest they are:</p> <p>Support for Science (including for experimental medicine) 50%</p> <p>Academic Medical Centres 10%</p> <p>Technology platforms 5%</p> <p>Leadership funding 10%</p> <p>Priorities and needs and support for smaller academic centres 25%</p>		

Question 11 – Programmes

a	Are the proposals for research programmes appropriate? YES/NO	YES
b	If not, what should we amend, add or delete?	
<p>Proposals for research programmes are broadly appropriate, though it is not clear whether university staff as well as NHS staff will be able to apply. Both staff categories should be eligible to apply</p>		

Question 12 – Research networks

a	Are the proposals for research networks appropriate? YES/NO	YES
b	If not, what would achieve the aims better?	
<p>The aims of these proposals seem reasonable. What is not clear is the exact role of the generic networks. Their level of funding will be crucial in determining their effectiveness especially if they are intended to cover the infrastructure requirements for all clinical areas other than the designated topic specific areas</p>		

Question 13 – Bureaucracy ‘busting’

a	Do you agree with our guiding principle that procedures and data input should occur once and once only and that where duplication exists, we will seek to streamline it? YES/NO	YES
b	Are the proposals for bureaucracy ‘busting’ appropriate ? YES/NO	UNCERTAIN
c	If not, what would achieve the aims better?	
<p>The principle of minimising data entry requirements is a sound one. How achievable some of these ambitions are technically remains to be seen – for example how related papers and impact of research will be detected by IT systems is unclear.</p> <p>The problem of excessive caution and inconsistency between organisations in the interpretation of governance and ethics requirements is indisputable. Research passports sound promising although it would be helpful to know exactly what they entail and</p>		

which processes they circumvent. It is also not clear what the process of governance checks on behalf of NHS Trusts actually means – does this mean a centralised system within a health economy to which all Trusts would sign up?
 Excessive and duplicative form filling is only part of the problem. The varied interpretations placed on governance/ethics items is arguably a greater issue

Question 14 – Transition

a	How important is it that our funding is allocated transparently?
It is important undoubtedly that funding is allocated transparently in order to correct historic anomalies and so that organisations may respond appropriately to measures aimed at incentivising research activity.	
b	How important is it that we establish a sustainable funding system?
Likewise sustainability of the arrangements is critical. This makes it doubly important that the financial flows in support of research do not vary unpredictably from year to year, whilst nonetheless allowing the system to respond to longer term secular trends in research activity (such as the anticipated steep increase in activity associated with the establishment of the new medical schools)	
c	How important is it that we establish a funding system that is responsive to changes in levels of research activity?
See response to 14b)	
d	How important is it that we do not lose momentum in the move to the new system?

Loss of momentum is undesirable	
e	If the implementation start date is 1 April 2006, how long should the transition to the new system take to complete: 1 year, 2 years, or 3 years?
Avoidance of destabilisation is important and to that end the transitional period should be 2 yrs or so.	
f	How important is it to ensure that we do not destabilise individual institutions as we move to the new system?
See response to 14e)	

Question 15 – Overall

a	By what criteria will you judge us on the impact of this strategy?
We would agree that the key performance measure enunciated in para 15.2 is entirely appropriate. Clearly this performance measure is the end result of a complex process and each of the component parts of the pathway will need to be enhanced. In particular the strategy needs to encourage the research energy of a wide range of organisations (not just a small number of world class centres, who alone cannot identify and recruit sufficient patients to achieve the desired result) and ethics and governance processes need to be rescued from their current precarious state	
b	Do you have any other comments?

Thank you for completing this questionnaire. Please save this document and email it as an attachment to RDconsultation@dh.gsi.gov.uk. For any queries or information, please contact this email address or telephone 020 7972 4113.

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<http://www.dh.gov.uk/Consultations/LiveConsultations/>.

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DH will report on the outcome of this consultation at the end of November 2005 at www.dh.gov.uk.