



## Review of the UK National Stem Cell Network

Final report prepared for

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## Executive Summary

### **Background**

The UK National Stem Cell Network (UKNSCN) was established to fulfil recommendation 10 of the Pattison report:

*'The Government should allocate additional funding to establish The UK Stem Cell Cooperative, to maximise the cross-fertilisation between those involved in the sub-disciplines of UK stem cell research.'*

Five high-level objectives were given to the UKNSCN as a result of the 2006 Town Meeting, which was called to discuss the establishment of the network and was attended by 75 members of the stem cell community. These objectives can be divided into two broad categories: 'networking' objectives that seek to encourage interaction between different groups in the stem cell field, and to facilitate the flow of information; and 'influencing' objectives to provide a voice for the stem cell community.

The UKNSCN is funded by a consortium of Research Councils, and hosted by BBSRC. The steering committee includes prominent researchers in different areas of stem cell science, as well as an industry representative and a social scientist. There is one full-time co-ordinator who provides the secretariat to the committee.

### **This review**

PSP was commissioned to undertake the review in July 2008. The key questions that we have investigated are:

- Is there a demand in the stem cell community for the UKNSCN? If so, for which activities or roles?
- How well has the UKNSCN discharged its current roles, defined by the five objectives it was given at the 2006 Town Meeting?
- Considering community demand and current performance, what is the most appropriate way for the UKNSCN to develop in future?

This review has been based on evidence gathered from written documentation provided by the UKNSCN, face to face and telephone interviews with a wide range of stakeholders, and 362 submissions from members of the stem cell community to an online questionnaire.

### **Networking objectives**

#### **Co-ordination of existing activities through the sharing of expertise and technology**

Responses to this review from members of the community reveal that there is a demand for an organisation to act as a hub for the dissemination of information about activities in the stem cell field. There is also strong support for an organisation to provide events that enable those from different disciplines with a shared interest in stem cell research to meet and interact. Although regional networks play these roles successfully within their own areas, the findings show that there is a need for activity at a UK level.



UKNSCN activity to promote this objective provides good foundations on which to build. The first annual meeting has been judged to have been a success by those who attended it, and has the potential to develop into a national stem cell symposium. The electronic bulletin was found to fill a need for information at a national level that can allow individuals and organisations to plan their diaries and activities as a result of knowing what others in the field are doing. There are improvements that could be made to the website.

### **Facilitation of interactions with users**

UKNSCN activity in this area has been limited to date. The commercialisation working group provides a good model of collective working by a range of different stakeholder groups. The UKNSCN should build on this. However, this review has found strong evidence that the UKNSCN is perceived as being more representative of, and interested in, perspectives from the research base than those in other sectors. For the UKNSCN to effectively fulfil a role in meeting this objective, respondents said it would need to engage more successfully with the business community.

### **National focal point for overseas researchers**

We have found clear evidence that there would be a benefit to stem cell research in the UK if an organisation was to successfully fulfil the objective of being a focal point for overseas researchers. In particular, stakeholders and respondents based overseas feel that this is an important role.

Regional networks provide good detailed information about activities, facilities and capabilities within their area, but they cannot provide a ‘one stop shop’ for enquiries about the UK, and some areas of the UK (including those containing important research groups) are not covered by active regional networks. Furthermore, the plethora of regional networks has been found to give a confusing profile of the UK to the international stem cell community.

As a UK wide organisation with connections to the research base, the UKNSCN has the potential to provide a hub for disseminating information about UK stem cell science to the outside world. However, there is evidence that the UKNSCN is not sufficiently well resourced to provide the range of service that would be most useful to potential overseas collaborators at this stage.

## ***Influencing objectives***

### **The national focal point for communication with the media and the public**

The evidence we have presented shows that there is not a role for a ‘focal point’ for communication with the media; not least because the media do not require it. Nevertheless, there is an evident desire among members of the UK stem cell community for the UKNSCN to have a communication role. Favourable public opinion is felt to be of great importance if this rapidly developing field is to continue to have a favourable regulatory environment in the UK. Many members of the community articulated a need for a credible UK wide organisation to provide resources on subjects of specific interest to



the public, and to be able to project information and messages on behalf of the community. This information could be delivered via the UKNSCN website.

### **The national voice of the stem cell community to policy makers and regulators**

Several stakeholders cited the favourable regulatory environment of the UK as key to the current strength of UK stem cell science. Nine out of ten respondents to the online questionnaire agreed that it is important for there to be an organisation to provide a voice for the community to policy-makers and regulators, and more than eight out of ten agreed that it would be helpful to them if the UKNSCN had a strong voice in regulatory debates. As a UK wide organisation the UKNSCN could play a role in contributing to the policy and regulatory debates regarding stem cell science.

The UKNSCN played a role in lobbying for the HFE Act 2008. However, there is a perception among stakeholders that the UKNSCN does not necessarily seek out the views of the wider stem cell community. This view seems to be reinforced by evidence from the online questionnaire, with only three out of ten respondents agreeing that the UKNSCN represents them to policy makers or regulators. Policy stakeholders expressed some scepticism that the UKNSCN could play a role in policy or strategy development as it currently operates, but said that the network could be able to play a useful role in future if it was seen to be a more consultative body.

### ***Relationship with the community***

Responses to the online questionnaire show that most members of the community do not tend to feel strongly attached to the UKNSCN. Furthermore, some stakeholders consider the UKNSCN to be lacking in transparency, and to not have built strong relationships with other relevant organisations in the stem cell field. These are areas that the network can build on in its next period of operation.

### ***Conclusions***

The evidence that we have gathered shows that there is a role for an organisation to pursue both the networking and influencing objectives for the UK stem cell community. However, the UKNSCN has not yet been able to fully fulfil these objectives.

We have found strong evidence that although the UKNSCN was established to fulfil the role of a network, it is perceived by many to be a committee. Although many connections have been made, the stem cell community have yet to develop strong feelings of membership/ownership of the network. This lack of development as a network also adversely affects the ability of the UKNSCN to fulfil 'influencing' roles.

To improve its effectiveness with the limited resources at its disposal, the UKNSCN needs to be able to focus strongly on developing its capacity to fulfil the 'networking' objectives. Above all, this requires the co-ordinator to have the resources and decision-making ability to function as a hub, able to organise events and distribute information among the many interested bodies in the stem cell field. In addition the co-ordinator needs strong strategic direction from organisations (not just individuals) that are significant within the UK stem cell environment.



## **Recommendations**

### **Focus of the network**

The central role of the network should be to facilitate the exchange of information between different people and groups in the stem cell field at a UK level. Until the UKNSCN can function effectively as a network, and can demonstrate that it is in touch with the concerns of the various parties involved in UK stem cell science, it can only play a limited role in policy formation. Development of the networking roles of the UKNSCN should therefore take precedence over the influencing roles.

**Recommendation 1:** The UKNSCN should re-focus its objectives to prioritise its networking role.

### **Staff resources**

A network requires a hub to enable and support the exchange of information, as well as to act as a repository of knowledge of community activities. The networking activities can be enhanced if effectively co-ordinated. A co-ordination role should facilitate information exchange and help people to make the appropriate connections.

The co-ordination function is currently carried out by one full-time member of staff. We have seen evidence that the demand for information from the UKNSCN exceeds its ability to provide such information at present. More than one full-time member of staff should be employed if the UKNSCN is to perform the range of tasks required to fulfil its networking function effectively.

**Recommendation 2:** The UKNSCN should appoint at least one more full-time member of staff to enhance its networking capacity.

### **Corporate structure**

The UKNSCN one year plan gives five possibilities for the future development of the network:

- Industry/trade association
- Public-private partnership
- Learned society
- Not-for-profit company limited by guarantee
- No change

Evidence from stakeholders suggests that the UKNSCN does not have strong enough links in the business community to operate as an Industry or Trade Association.

Many stakeholders expressed concerns that direct commercial funding, even as part of a public-private partnership, would prejudice perceptions of the independence of the UKNSCN. For this reason, we believe that a public-private partnership is not an appropriate model for the UKNSCN at this stage.

We have not found a strong demand among interviewees for a Learned Society in the stem cell field at this point, and also do not think that a subscription funded model would generate sufficient funding or membership at this point in the UKNSCN's development.



The online survey provides evidence that members of the community do not currently feel a strong sense of attachment to the network.

The most active regional networks are established as not-for-profit companies. This model adopted by these active regional networks is effective. However, at present the UKNSCN has a wide remit and limited resources. The in-kind contributions that it receives from BBSRC, including physical hosting and access to an experienced press officer, are of substantial value. We do not recommend that the UKNSCN becomes an organisation independent of the Research Councils if it would mean losing access to these resources, unless similar cash or in-kind contributions are available.

**Recommendation 3:** The UKNSCN should continue to be hosted by the Research Councils.

### **Governance**

The direction of the network should be set by those with connections to and knowledge of the activities of the other organisations who are providing information and networking services in the Stem Cell field. Governance of the network by those with such breadth of strategic vision would help to minimise duplication of the activities of other organisations. By avoiding duplication and finding synergies with other organisations, the UKNSCN could act more effectively and ensure that it provides better value for money to the UK tax-payer. The board should be comprised of the funders of the network to ensure accountability for expenditure, and should therefore govern the activities of the co-ordinator.

**Recommendation 4:** A management board should be established to direct the network, and other public and charitable bodies active in the stem cell field should be invited to contribute funding to the UKNSCN and thus qualify to sit on the board.

### **Advisory support**

It is essential that the UKNSCN remains closely connected with key figures in the stem cell community. The steering committee (as currently constituted) should play an advisory role, becoming an expert advisory committee to the network. It should offer advice about the management and direction of the network, with the Chair of the advisory committee invited to join the management board of the UKNSCN. In addition, the committee should play a role in enabling the UKNSCN to connect with, and reflect the views of, the stem cell community. This should involve supporting working groups comprised of members of the community, advising on consultative and networking activities, and other activities as decided by the UKNSCN.

**Recommendation 5:** The role of the steering committee should be modified so that it plays a strong advisory role. The chair of this Expert Advisory Committee should be invited to join the UKNSCN management board.



# 1 Introduction

Recommendation 10 of the UK Stem Cell Initiative<sup>1</sup> report was that the government establish a body “to maximise the cross-fertilisation between those involved in the sub-disciplines of UK stem cell research”. As a result of a stem cell community Town Meeting held in 2006, the UK National Stem Cell Network (UKNSCN) was formed. The Town Meeting decided that the network should be reviewed after two years of operation, and this report contains the findings of that review.

## 1.1 Remit of this review

BBSRC commissioned this review of the UKNSCN:

- to review the progress made against the objectives identified by the scientific community attending the Town Meeting on 6 July 2006;
- to determine the perceptions of the community about:
  - the current role of the UKNSCN in meeting the needs of the scientific community; and
  - how the UKNSCN should develop in the coming years;
- to consider current and potential sources of funding to support UKNSCN activities; and
- to report the findings to the stem cell community and the sponsors of UKNSCN.

PSP was commissioned to undertake the review in July 2008. The key questions that we have investigated are:

- Is there a demand in the stem cell community for the UKNSCN? If so, for which activities or roles?
- How well has the UKNSCN discharged its current roles, defined by the five objectives it was given at the 2006 Town Meeting?
- Considering community demand and current performance, what is the most appropriate way for the UKNSCN to develop in future?

## 1.2 Review Methodology

This review has been based on evidence gathered from six sources:

- Written documentation provided by the UKNSCN
- Face to face interviews with the UKNSCN co-ordinator, press officer, and members of the steering committee
- Telephone interviews with a sample of key decision makers and opinion formers in the stem cell community
- Telephone interviews with journalists
- 362 submissions to an online questionnaire from members of the stem cell community
- Follow-up telephone interviews with respondents to the online questionnaire

Further details about the review methodology can be found in the technical appendix.

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<sup>1</sup> Report & Recommendations of The UK Stem Cell Initiative, November 2005, p8



### **1.2.1 Definitions**

In this report, we refer to data from the interviews as having come from ‘stakeholders’, and data from the online submissions as having come from ‘respondents’.

Where we refer to ‘regional’ networks in this report, we mean all the stem cell networks that represent specific geographical areas within the UK; therefore including the Scottish Stem Cell Network (SSCN) as well as networks that represent the English regions.

### **1.3 *This report***

Chapter two of this report provides some background to the establishment of the UKNSCN. Chapter three takes each of the objectives that relate to ‘networking’ in turn; first discussing the evidence that they reflect needs in the stem cell community, and then considering evidence of the performance of the UKNSCN in meeting those objectives. Chapter four examines the objectives that relate to ‘influencing’ in the same way. Chapter five considers the relationship of the stem cell community to the UKNSCN, and Chapter six gives conclusions from this review. Chapter seven presents recommendations for the development of the UKNSCN. Technical details of the methodology can be found in the technical appendix of this report.



## 2 Background

### 2.1 The UK Stem Cell Initiative

In his Budget speech in March 2005, the then Chancellor Gordon Brown stated:

*“our aim must be that Britain becomes the world's leading location for research-based, science-based and knowledge-based industries.*

*Stem cell research holds the key to tackling some of the world's most intractable diseases from diabetes to Parkinsons. I firmly believe that Britain can be a world leader.”*

This speech launched the UK Stem Cell Initiative, charged with developing a ten-year vision for UK stem cell research, to be implemented between 2006 and 2015. The Initiative was chaired by Sir John Pattison, and after six months of consultation its report was published in November 2005.

The ‘Pattison Report’ made 11 recommendations. Recommendation 10 was:

*‘The Government should allocate additional funding to establish The UK Stem Cell Cooperative, to maximise the cross-fertilisation between those involved in the sub-disciplines of UK stem cell research.’*

The full text of the Recommendation reads:

*‘One of the crucial elements currently missing from UK stem cell research is a national cooperative, network or forum, for the interaction of scientists, clinicians, ethicists, policy-makers, regulators and commercial organisations with an interest in stem cell research.*

*Stem cell researchers have recognised the need for such associations and established them at regional levels, such as the Scottish Stem Cell Network, the East of England Stem Cell Network and the London Regenerative Medicine Network. A UK-wide cooperative would promote the exchange of ideas and actively facilitate collaboration within both the public and private sectors across the breadth of UK stem cell research.*

*The UK Stem Cell Cooperative should host regular meetings and establish efficient mechanisms to exchange information and ideas in the area. The Cooperative should also work with the International Stem Cell Forum on the characterisation of stem cell lines, the ethical landscape and intellectual property issues.’*

The ‘Pattison Report’ costed this proposal at somewhere between £400,000 and £600,000 per annum to implement. This costing indicated the type of activities that were envisaged: an annual international scientific meeting, regular national meetings, website maintenance and administrative costs.



## **2.2 The 2006 Town Meeting**

The UK National Stem Cell Network (UKNSCN) was established to fulfil recommendation 10 of the Pattison report. Following an online consultation with the community, three options for the form of the network that were believed to be most likely to gain support were put to the stem cell community at a Town Meeting in 2006. These were:

- a body based at the UK Research Councils with an internationally-recognised director;
- a body based within a regional stem cell network; and
- a body based in a new Scientific Society.

Although the majority of the 75 attendees agreed that the UK required a body to act as the national voice for the UK stem cell community, no consensus was reached regarding the three proposed models, and instead an interim arrangement was agreed. A steering committee with a secretariat was established with a Chair Person independent of any of the existing regional networks. The community itself was to nominate the Chair and steering committee members, and the arrangement was to be reviewed after two years with a view to possible relocation and evolution of its role.

The town meeting decided that the network should have the following characteristics.

The UKNSCN should:

- be flexible and responsive;
- be open and inclusive in its membership;
- be fully representative of UK interests in stem cells; and
- be independent and accountable with measurable outputs.

The UKNSCN should not:

- replace or replicate the activities of existing networks;
- sponsor scientific research; or
- broker exploitation activities.

### **2.2.1 Structure of the UKNSCN**

As established, the UKNSCN is funded by a consortium of Research Councils. BBSRC and MRC each contribute £50,000 per annum. EPSRC and ESRC each contribute £25,000. In addition, BBSRC physically host the UKNSCN and therefore provide in-kind contributions such as office space, web-hosting, and the services of the BBSRC press officer on a part time basis.

Applications for the role of co-ordinator to the network were invited through national advertising, and the current co-ordinator was therefore appointed through open competition. Steering committee members were appointed on the basis of nominations from members of the UK research community, together with considerations of specific scientific expertise in certain types of stem cell research, and UK geographic representation.



## 2.2.2 Objectives of the UKNSCN

Five high-level objectives were given to the UKNSCN from the Town Meeting. They can be divided into two broad categories: ‘networking’ objectives that seek to encourage interaction between different groups in the stem cell field, and to facilitate the flow of information; and ‘influencing’ objectives to provide a voice for the stem cell community.

### Networking objectives:

We have called the UKNSCN objectives that most closely reflect the spirit of recommendation 10 of the Pattison Report the networking objectives. These objectives require the UKNSCN to be capable of connecting people from different backgrounds and institutions within the stem cell field, and to instigate activities that lead to contacts and interactions between people who represent the variety of groups with an interest in the stem cell field. The networking objectives are:

- the co-ordination of existing activity through sharing knowledge;
- to facilitate interactions to promote uptake and use of stem cells by the scientific, business and medical communities; and
- to be the national focal point for interaction with overseas researchers seeking collaboration.

### Influencing objectives:

The town meeting also established two influencing objectives, which are:

- to be the national focal point for communication with the media and the public; and
- to be the national voice of the stem cell community to policymakers and regulators.

## 2.3 UKNSCN overview

The UKNSCN has eight steering committee members and a chair, Lord Patel of Dunkeld. The steering committee includes prominent researchers in different areas of stem cell science, as well as an industry representative and a social scientist. Several members of the steering committee are involved as Directors of, or advisors to, the main regional stem cell networks. The committee has held ten meetings since December 2006. There is one full-time co-ordinator who provides the secretariat to the committee, and much of his work-plan is set during these meetings. Working groups involving committee members are also initiated during the main committee meetings.

The UKNSCN is a virtual organisation run by the BBSRC. It is financially accountable to the Cross Council Stem Cell Co-ordinating Committee (CCSCCC<sup>2</sup>), and reports its activities to the UK Stem Cell Funder’s Forum (UKSCFF) for further dissemination, although the operations of the UKNSCN have been directed by the steering committee.

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<sup>2</sup> This comprises the Biotechnology and Biological Sciences Research Council (BBSRC), the Medical Research Council (MRC), the Economic and Social Research Council (ESRC), the Engineering and Physical Sciences Research Council (EPSRC), the Science and Technology Facilities Council (STFC), the Technology Strategy Board (TSB), the Department of Health (DH) and the Department for Innovation, Universities and Skills (DIUS)



The UKNSCN has held one annual meeting which had 360 attendees, in Edinburgh in April 2008, with a second to take place in Oxford in April 2009. In addition, it has held meetings with stakeholders on subjects such as barriers to the commercialisation of stem cell research. A variety of other activities have been undertaken, and these are discussed in relation to each of the UKNSCN objectives in chapters 3 and 4 of this report.



### 3 Networking objectives

Recommendation 10 of the Pattison Report described the establishment of a body “to maximise the cross-fertilisation between those involved in the sub-disciplines of UK stem cell research”<sup>3</sup>. The three objectives that we discuss in this chapter are most relevant to this recommendation.

This chapter considers each of the networking objectives in turn, discussing first the evidence that there is a need in the community for an organisation to address that objective, and secondly the performance of the UKNSCN in doing so to date.

#### 3.1 Co-ordination of existing activities through the sharing of expertise and technology

##### 3.1.1 Rationale for objective and evidence of demand

One of the UKNSCN objectives is to *co-ordinate existing activities through the sharing of expertise and technology*. The co-ordination referred to in this objective requires information about different activities in the stem cell field to be made widely available, so that different actors can plan their activities effectively, and that the sharing of information may help to reduce duplication, and create opportunities for collaboration. We have found evidence for demand that an organisation should play this role in the stem cell field.

One stakeholder we spoke to thought there was a role for an organisation to bring together people with different backgrounds who are involved in stem cell research, including clinicians and research scientists:

*“...so that you start to get a bit of synergy between people who have different backgrounds and different interests, to try and develop ideas that were currently in the lab but that could be moved forward to the clinic, but also clinicians informing laboratory scientists as to what their needs are for the patients.”*

Policy stakeholder

This is the role played by regional networks within their areas, and the original Pattison report recommendation drew on these networks as an example on which to base the UK-wide organisation. This can be done principally by:

- hosting meetings, workshops and other events through which people from different groups can interact;
- disseminating information about events and opportunities taking place, via website and newsletters; and
- giving people relevant contacts in the field in response to ad-hoc enquiries.

In the online questionnaire we asked whether some proposed UKNSCN activities to promote co-ordination and sharing would help respondents.

Demand for web-based facilities was strong. As Figure 3.1 shows, most respondents (73%) agreed that development of the UKNSCN website as a collaborative tool for

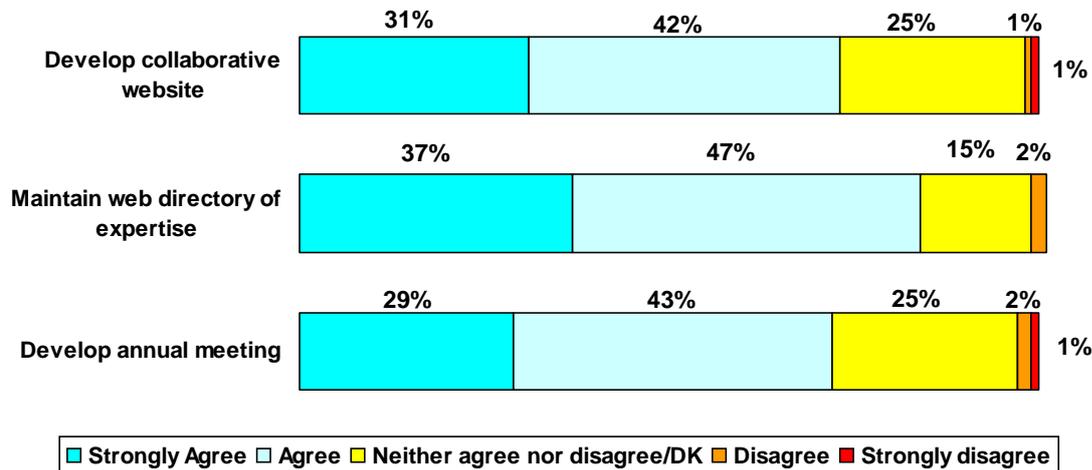
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<sup>3</sup> Report & Recommendations of The UK Stem Cell Initiative, November 2005, p95



researchers would help them (including 80% of the academic researchers who responded). There was even greater support for the maintenance of a web-based directory of expertise across the sub-disciplines of stem cell science, with 84% of respondents agreeing that this would help them. Demand for this was especially strong from respondents based overseas.

**Figure 3.1: It would be helpful to me if the UKNSCN were to...**



Base: All who answered (360, 358, 357)

There was also demand for the continued development and expansion of the UKNSCN annual meeting, with 72% of respondents agreeing that this would help them. It is interesting to note that among respondents who had not been able to attend the first UKNSCN annual meeting in April 2008, a majority (56%) thought it likely that they would attend UKNSCN annual meetings in future, including one in five (21%) who thought it very likely, indicating demand for such meetings.

### 3.1.2 Performance

The UKNSCN has delivered several co-ordination activities. These include:

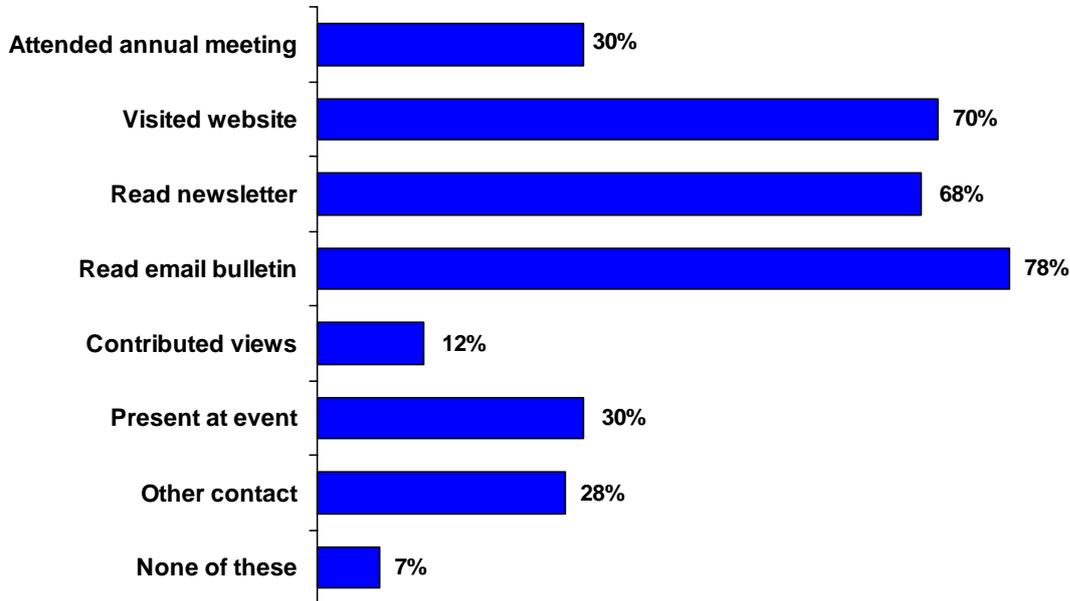
- The inaugural conference at the Edinburgh Conference Centre, April 2008
- Electronic events bulletins produced every month
- Presentations about the network to UK and overseas audiences including academics, regional networks, industrialists and the Foreign and Commonwealth Office (FCO)
- The establishment of an on-line discussion forum on the UKNSCN website
- The establishment of a network of contacts in academic institutions through whom enquiries can be distributed

Figure 3.2 shows the proportion of respondents to our online survey who have had contact with the UKNSCN in different ways. The great majority of respondents (85%) had read either the e-mail bulletin or the e-mail newsletter. This is not surprising considering that those we contacted to take part in the online survey were drawn from the UKNSCN mailing list. Half had also attended either the UKNSCN meeting or another UKNSCN event, or had attended a presentation given by the co-ordinator or a steering committee member. Three in ten (28%) had made contact with the UKNSCN for other reasons. These were predominantly to ask for contact information of scientists working in a



relevant area of science; to ask for funding; or requests to disseminate information through the UKNSCN newsletter.

**Figure 3.2: Contact with the UKNSCN**



Base: All respondents (362)

The **inaugural UKNSCN annual meeting** took place between the 9<sup>th</sup> and 11<sup>th</sup> April 2008. The meeting was well attended, with 360 delegates, 30 trade exhibitors and 85 posters.

Feedback about the inaugural meeting has been generally positive. Three out of ten (30%) respondents to the online questionnaire had attended the meeting, and as Figure 3.3 shows, half (50%) of those found the meeting very useful, with most of the remainder reporting that it was fairly useful. An important endorsement is that among those who attended most were either very (53%) or fairly (40%) likely to attend future UKNSCN meetings.

The meeting contributed in a real way to the sharing of expertise and technology. Nearly four in ten (37%) respondents who attended the meeting said that they had discussed collaborative working or engaged in joint work as a result. Some examples include:

*“Contacts made during the poster session have resulted in another group visiting our labs to learn techniques.”*

UK research scientist

*“We had a trade stand at the meeting and have since had discussions with several groups we met at the meeting. Some with a view to sales, others for non-sales based collaborations.”*

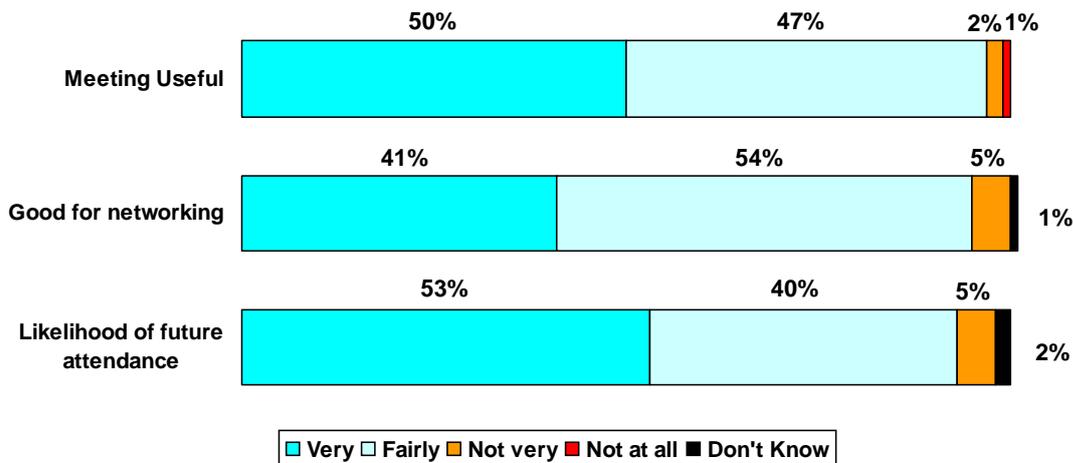
UK commercial scientist

*“Ongoing collaborative work with another attending group and [had] several valuable discussions both with the guest speaker and other adult stem cell researchers at the conference dinner.”*

UK research scientist



**Figure 3.3: Feedback from those who attended the inaugural meeting**



Base: All who attended the meeting and answered (108) (108) (107)

Although feedback from those who attended the meeting was very positive, there were also critical voices. Some thought that as there are many stem cell meetings already, another is not necessary. In addition, a few mentioned that some of the most distinguished members of the UK academic stem cell research community were not present at the first UKNSCN meeting, and that it cannot be considered as successful as if they had attended.

Despite this, it should be remembered that this was the first meeting, and it may take some time to become established. Other stakeholders considered that the meeting provided a good opportunity for younger researchers to mingle with established scientists in the field, and that it has therefore made a contribution to career development of a younger cohort of scientists. The meeting has also served as a forum for those with backgrounds in social science and law as well as natural science, and has therefore contributed to strengthening links between those from a variety of disciplines who have an interest in the stem cell field – which was central to recommendation 10 of the Pattison report.

The UKNSCN distributes **electronic bulletins** on a frequent basis, and has to date produced two electronic newsletters. The electronic bulletins are distributed to an international mailing list of more than 1000 people. The bulletins include information on stem cell meetings in the UK and overseas, funding opportunities, and other information that may be relevant to people with an interest in stem cell research.

The newsletters tend to be valued by those who receive them. One UK academic we interviewed said:

*“When you look at the UK annual meeting, and the bulletin, you look back and think ‘that was mad that we didn’t have that before’. They are things that absolutely had to be there.”*

UK research scientist

Positive feedback about the electronic newsletters was given by those who responded to the online questionnaire. Most (88%) said that they found the bulletins to be ‘very’ (26%) or ‘fairly’ (62%) useful. Comments from those who found the bulletins to be ‘very useful’ include:



*“There is no other bulletin that provides a better overview of what is going on in terms of UK stem cell science activities.”*

UK Civil Servant

*“It is the glue the binds the community.”*

Commercial researcher

Feedback from those who said it is fairly useful included:

*“One-stop shop for UK Stem Cell related news. I forwarded a Canadian SCN offer to a colleague and he's now traveling to Vancouver and Toronto.”*

Academic researcher

*“Actually quite good, but very limited time to read it amongst everything else that passes my desk.”*

Academic researcher

Feedback on the **UKNSCN website** tended to be more mixed. Some stakeholders we spoke to felt that it did not provide a comprehensive source of information about stem cells, or links to relevant resources. Those who completed the online questionnaire and had visited the website affirmed that they had found it either very (20%) or fairly (67%) useful. Some of those who found it ‘very useful’ said:

*“The UKNSCN is a focal point for finding information about UK stem cell science and enabled me to get an overview of what was going on in this area.”*

UK Civil Servant

*“I found the information I was looking for.”*

Academic researcher

Many of those who found it ‘fairly useful’ qualified this endorsement by suggesting that extra features could be added:

*“It was easy to navigate and had good information for the research community. Seemed to be lacking in public information, perhaps this is not a target audience, however, even media could stand to have comprehensive backgrounders available in a downloadable format.”*

Press Officer

*“Well done, maybe more links to other stem cell resources?”*

Academic researcher

*“Not as much information on there as there might be perhaps?”*

Charity administrator

One stakeholder felt that it was important for the UKNSCN website to provide a broader range of information relevant to stem cell policy:

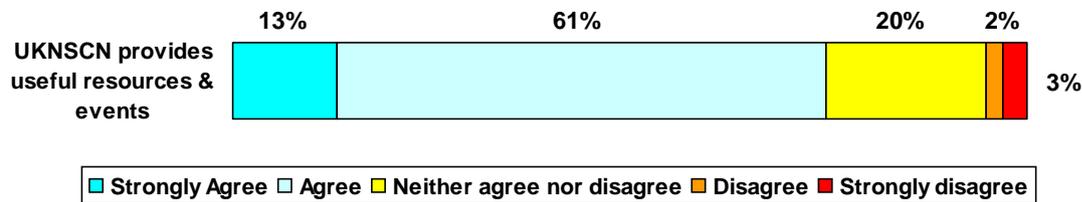


*“A criticism of their website would be that if you go on there, and you look for downloadable documents, there are a lot of reports and papers out there [on the internet], but they are not there. It is the report that helped set them up, but not the other documents. So as a resource are they providing anything that it isn’t possible to google? I suspect not really.”*

Policy stakeholder

An expansion of the information that can be accessed through the website could enhance the networking role of the UKNSCN by signposting people to a broad range of other organisations and resources that would be useful to them. The website could also play a greater role with regard to the UKNSCN’s offering to the public, policy makers, and overseas researchers. As shown in Figure 3.3, feedback from respondents to the online questionnaire suggests that the provision of a web-based directory of expertise would be helpful to a large proportion of the stem cell community.

**Figure 3.4: The UKNSCN provides useful resources and events**



Base: All who answered (353)

Figure 3.4 shows that three out of four (75%) respondents to the online questionnaire agree that the UKNSCN provides useful resources and events, but just over one in ten (13%) strongly agree. This indicates that although there is goodwill towards the organisation it has more to do in order to demonstrate that it is very valuable to most members of the stem cell community.

### 3.1.3 Summary

Responses to this review from members of the community demonstrate that there is a demand for an organisation to act as a hub for disseminating information about activities in the stem cell field. This is shown by the strong support for the creation of an online directory of expertise. There is also strong support for an organisation to provide events that enable those from different disciplines with a shared interest in stem cell research to meet and interact. Although regional networks play these roles successfully within their own areas, it was said that there is a need for activity at a UK level.

UKNSCN activity to promote this objective provides good foundations on which to build in the next period. The first annual meeting has been judged to have been a success by those who attended it, and has the potential to develop into a national stem cell symposium. The electronic bulletin fills a need for information at a national level that can allow individuals and organisations to plan their diaries and activities as a result of awareness of what others in the field are doing. There are improvements that could be made to the resources offered by the website, so that it develops into a more useful information resource for the stem cell community, although this has been recognised by the UKNSCN in the proposals for development contained in its one year delivery plan.



### 3.2 Facilitation of interactions with users

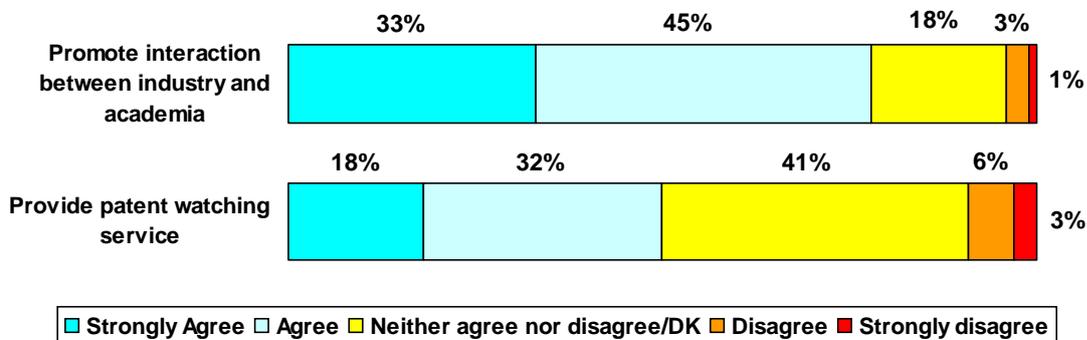
#### 3.2.1 Rationale for objective and evidence of demand

The UKNSCN aims to *facilitate interactions to promote uptake and use of stem cells by the scientific, business and medical communities, particularly in the areas of tissue engineering and regenerative medicine*. This objective implies a role in promoting the translation of stem cell science into therapies. Activity to fulfil this objective can be pursued in various ways, including meetings through which scientists, clinicians and industrialists can meet and discuss issues of common interest, and the identification of barriers to translation.

Interviews with stakeholders revealed that many feel facilitation of interactions between the scientific, business and medical communities to be important. In particular, some interviewees remarked that there are insufficient opportunities for those in the biotech industry to foster personal contacts with academic researchers, since there are limited opportunities for the two groups to mingle. This is a role that has been discharged successfully by some of the regional networks.

As Figure 3.5 below shows, four in five respondents (79%) reported that events and other activities that promote interaction between industry and academia would be helpful to them. A smaller proportion (50%) reported that a patent watching service would be beneficial. This does not of course imply that patent watching is less important to UK stem cell science; just that fewer respondents find it to be directly relevant to them.

**Figure 3.5: It would be helpful to me if the UKNSCN were to...**



Base: All who answered (360) (359)

#### 3.2.2 Performance

Activities that the UKNSCN has undertaken to fulfil this commercialisation objective include:

- Documentation on barriers to the commercialisation of stem cell research prepared by the steering committee, and the pending establishment of a national policy sub-group on commercialisation to begin overcoming those barriers
- Participation on patenting issues in stem cell research, and how this affects progress of research and translation

This area is one in which the UKNSCN has not yet undertaken a great deal of activity, although sessions on patenting were held during the annual meeting. A commercialisation



working group has been assembled which includes representatives of charities and industry as well as research scientists and clinicians. Several meetings or workshops have been held so far. We spoke to stakeholders who have taken part in the working group, and in general they thought it was a productive exercise that had the potential to identify areas requiring legislative or policy attention.

*“I was happy to contribute to that first meeting and can hopefully work further with the other individuals in preparing this paper which hopefully will go up the food chain, all the way up in terms of making recommendations on what the challenges are and potentially how they could be resolved”*

Stakeholder

The commercialisation working group was thought by a policy stakeholder to have the potential to provide useful information as a result of bringing a range of stakeholders together to think about these problems.

However, several stakeholders said that they perceive the UKNSCN to be primarily for academic researchers, and believe that it has not yet fostered strong links with the business community.

*“My background understanding was that it was meant to be a single focal point, a portal, a voice box for stem cells UK plc, and what isn’t transparent at the moment is the industry aspect of things. There’s a lot that’s emphasised at the academic level, I would just say that there’s a lot more that can be done [to reflect industry needs].”*

Stakeholder

One way to establish better links between industry and academia may be for the UKNSCN to forge stronger links, or organise events jointly, with industry associations such as the Association of British Pharmaceutical Industry (ABPI), the Bio-Industry Association (BIA) and Bio-Process UK, the Knowledge Transfer Network for the Bio-technology sector. If the capacity of the UKNSCN to build such connections could be strengthened, this would in turn enhance its ability to facilitate interactions.

### **3.2.3 Summary**

In recommending the establishment of the UKNSCN, the Pattison Report recognised that the interdisciplinary requirements of translation of stem cell research means that those from different disciplines need to come together at a UK level to achieve the potential of the UK in this arena.

UKNSCN activity in this area has been limited to date. The commercialisation working group provides a good model of collective working by a range of different stakeholder groups. The UKNSCN should build on this. However, this review has found strong evidence that the UKNSCN is perceived as being more representative of, and interested in, perspectives from the research base than those in other sectors. For the UKNSCN to effectively fulfil a role in meeting this objective it would need to engage more successfully with the business community.



### 3.3 National focal point for overseas researchers

#### 3.3.1 Rationale for objective and evidence of demand

Several overseas interviewees confirmed that the UK is acknowledged as one of the world leading locations for stem cell research. This has led to a lot of overseas interest in UK science in this area. The UKNSCN is tasked with being *the national focal point for interaction with overseas researchers seeking collaboration*. This suggests that the UKNSCN has both a role to play in providing information about the UK and contacts within the UK to overseas researchers seeking collaboration; and that the UKNSCN could play a role in providing information to UK researchers or organisations about conditions and opportunities that exist for collaboration with overseas researchers.

The prevailing view among the stakeholders to whom we spoke was that this was an important role for an organisation to occupy in the stem cell field. However, some argued that non-UKNSCN sources of information and contacts are sufficient.

One view expressed was that the leading researchers in the field can easily be identified, and that in any case researchers in the stem cell field tend to know each other. Researchers can be identified from their published papers and contacted at their faculties via publicly available e-mail and telephone numbers. Whilst this is likely to be true for researchers who have achieved global visibility through their research, a space seems to exist for information provision on a different level.

At present, there is no central point that collates information about the full range of stem cell research groups and facilities in the UK. Some respondents expressed a desire to be able to access such information through the Internet and/or through an organisation able to turn around requests for information quickly by e-mail or over the telephone. This could enhance chances for collaboration with groups overseas that are not aware of all the possibilities that exist in the UK. Not all overseas scientists have a clear view of their potential collaborators in the UK. Because of the pace at which stem cell science is developing and the resources that some overseas governments are dedicating to this area, scientists from related areas of cell biology are interested in collaboration with UK groups but need information about who is most relevant. This is even more likely to be the case for overseas biotech companies, who may be interested in collaboration but do not have information about who in the UK would be most able to help them.

*“I know there’s a lot of interest [in the US] in finding out who’s doing what. I met with a scientist who has a small start up company, but very well funded. And they asked if I had any way of figuring out who’s doing what in the UK, ‘we’re looking for certain technologies that we would love to license or collaborate on. But is there any place I can look – a website or a database?’ I wasn’t able to refer him to anything.”*

Civil servant

UK-based scientists and organisations interested in seeking overseas collaboration would benefit from having access to an organisation that could provide reliable and up-to-date information about regulatory systems in other countries.



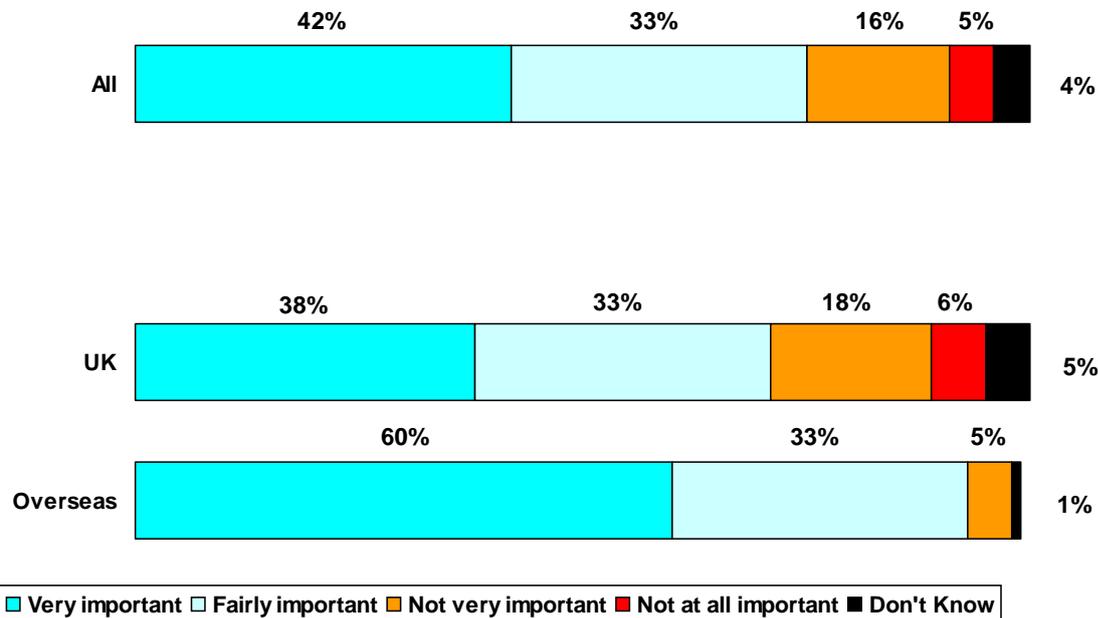
*“It would be useful if someone knew what is happening overseas, and what the regulatory systems are, and could therefore provide guidance for people who want to collaborate, or who want to fund a multi-national project.”*

Charity stakeholder

It is clearly in the interest of UK stem cell science to have strong connections with scientists overseas. Fostering connections now represents an investment for the future. Furthermore, without an organisation to provide a focal point for UK science with overseas researchers, collaborations may only be considered with those who are already highly visible. This could lead to opportunities for collaboration between tomorrow’s leaders in the UK and overseas partners being lost because the next generation of researchers currently have lower profiles.

The sense that being a focal point for overseas researchers is an important role for an organisation to play was reinforced by answers to the on-line questionnaire. Three quarters (75%) agreed that it was an important role, and only one in five (20%) disagreed. Those based overseas were more likely to value the importance of this role than those based in the UK. As figure 3.6 shows, nine out of ten overseas respondents (93%) thought it was an important role, and six out of ten (60%) thought it to be very important.

**Figure 3.6: How important is it to you that there is an organisation providing a UK national focal point for interaction between the UK stem cell community and overseas researchers?**



Base: All who answered; All (351), UK based (278), based overseas (73)

### 3.3.2 Performance

Activity that the UKNSCN considers to have contributed towards being a focal point for overseas researchers includes:

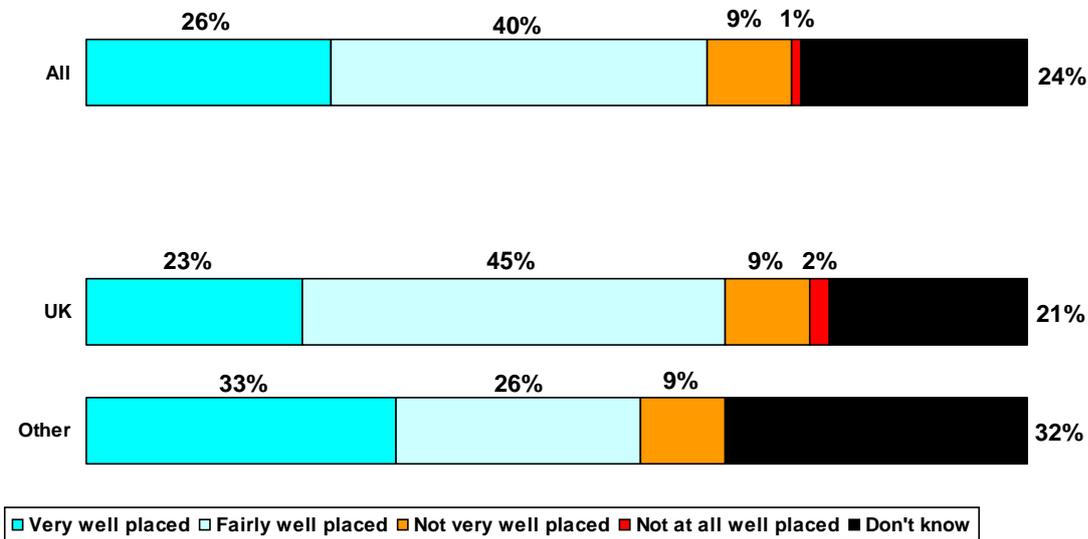
- The distribution of information about UK initiatives to overseas researchers
- Delivery of presentations to overseas researchers



- Establishment of contact with Canadian, Swiss, and Indian Networks, and the International Consortium of Stem Cell Networks (based in Australia)
- Opening negotiations with networks in Singapore and India to arrange bilateral workshops
- Co-location of exhibition stand with regional networks at International Society for Stem Cell Research (ISSCR) conference

Respondents to the online questionnaire who thought that it was important that an organisation provided a UK focal point for overseas researchers were asked whether they thought the UKNSCN was well placed to act as the focal point. Two-thirds of these respondents (66%) thought that it was. While a lower proportion of overseas respondents felt that it was well placed (59%), a higher proportion felt it was very well placed (33% of overseas respondents compared to 23% of UK respondents).

**Figure 3.7: How well placed is the UKNSCN to be the UK national focal point to overseas researchers?**



Base: All who thought that this role was important (262), UK based (196), based overseas (66)

Many of the respondents who thought the UKNSCN was very well placed wrote that this was because of its national status:

*“As this is a national level organisation and not just a local network. I am not from the UK but have benefited from UKNSCN interaction - especially since the participation in the discussion [at the annual meeting] was international and not limited to the UK.”*

Research scientist based in Asia

*“Providing one national voice and clearing house for staging collaborative interactions provides for more efficient communication of opportunities. This is where I would check first.”*

US research scientist



*“Similar networks for stem cell science exist in other countries and UKNSCN provides excellent opportunities for establishing collaboration.”*

Research scientist

Those who responded that the UKNSCN was ‘fairly well placed’ often tended to qualify their support by remarking that people have existing contacts and other channels and that the UKNSCN cannot therefore be the single focal point; or by questioning how high the UKNSCN profile is among potential overseas collaborators.

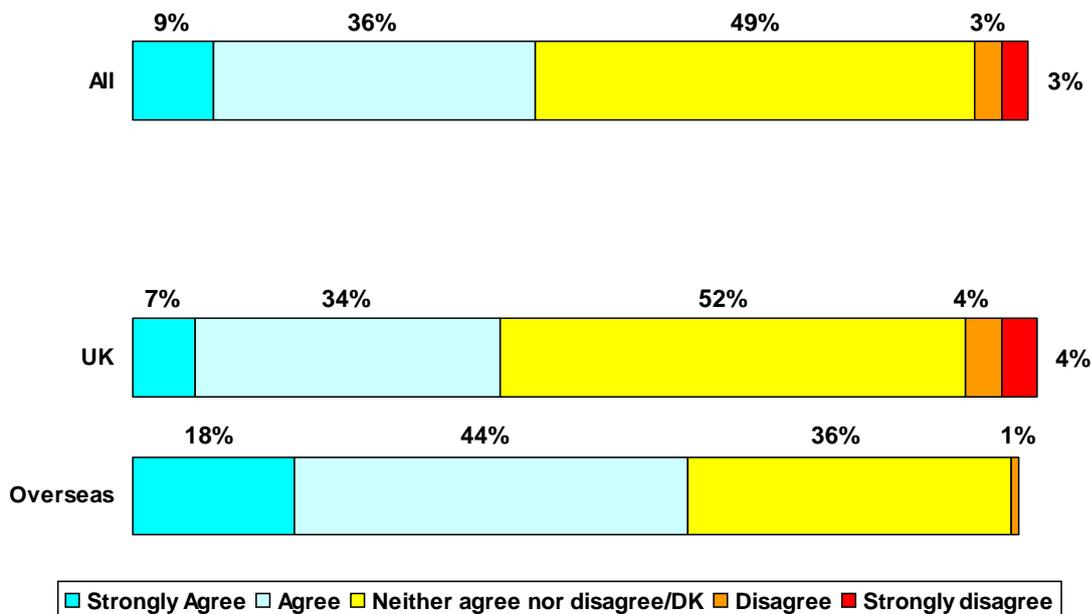
It should be noted that as shown in figure 3.7 below, those based overseas are more likely to think that the UKNSCN represents the UK stem cell community positively overseas than those based in the UK. This represents a greater endorsement from those more likely to know about the profile of the UKNSCN outside of the UK.

To some extent the existing networks in the UK can play a part in providing detailed information about the research groups and facilities in their area. However, researchers from overseas reported being confused by the number of networks in the UK. To some, the existence of the regional networks gives the impression that stem cell science in the UK is fragmented:

*“You go to an international stem cell conference and there’s six booths from Britain and you don’t think ‘wow, it’s obviously a fantastically vibrant stem cell culture’, you think ‘which way is up, do they know?’”*

Overseas respondent

**Figure 3.7: The UKNSCN represents the UK stem cell community to overseas researchers in a positive way**



Base: All who answered (354), UK based (282), Overseas based (72)

Some stakeholders felt that the regional stem cell networks behave very competitively, whilst failing to realise that the real competition is from other countries. Our interviews with those based overseas revealed that many think the visible existence of well funded



regional networks on the international stage is harmful to the UK, and that it presents an image of disunity. While there has been some attempt to reduce this by co-locating conference stands, the perception of a fractured stem cell community in the UK remains. It is arguable therefore that initial contacts with researchers overseas should be co-ordinated through the UKNSCN.

There is clearly interest in UK stem cell science from overseas. We interviewed a member of the Foreign and Commonwealth Office Science and Innovation Network, who explained the US Science and Innovation Network's interest clearly:

*“We often get [enquiries about potential collaboration in the UK], for example from researchers in California, where stem cell research is a fairly new field. Established scientists are now reformulating their work into the stem cell area, because before there wasn't any funding in it. Which means they're not necessarily that well linked in with the stem cell research community overall. Of course the UK has been in that space much longer and is a leader. We often get questions – ‘I would really like to work with someone on this and that’ and then they ask me who they should approach in the UK.*

*From our view, it is a very good time to establish collaborations between the UK, California and the wider US. The strength of biotech research here means that they are going to – not necessarily forge ahead, but they're going to catch up very quickly to the same level as UK stem cell research. The more connections we can foster between the two, the more likely it is that the UK benefits from having this strong partner in the future. California are also looking to a lot of other places in the world - Canada, Australia for example...”*

US Science and Innovation Network Stakeholder

The interviewee had contacted the UKNSCN for help and found it helpful. However, the UKNSCN was unable to provide the level and speed of assistance necessary, and contact with regional networks, although often helpful, did not provide information about areas of the UK that are not currently served by regional networks. They went on to explain how a better resourced UKNSCN would be of greater help:

*“To make it easier for interested parties to contact and enquire about possible collaboration, licensing or even starting or localising some of their research in the UK. It would be wonderful to have a single point of call, who can refer to the other networks or to [UK Trade and Investment] – just to know who to go to is very valuable and I think it is a great opportunity for the UKNSCN to fulfil this role.”*

US Science and Innovation Network Stakeholder

Some co-ordinators of the regional networks also explained that they thought the UKNSCN could play a greater role in providing a focal point for overseas researchers:

*“We've had two groups from overseas, when the organisers wrote to me to see if I would host these delegations, they didn't even know that the UKNSCN existed and when I suggested that they might want to go knocking on their door first, on the basis that the national network could co-ordinate a tour round the UK, we said ‘there is no point coming that distance just to [this region], if you're a group you might as well go*



*to the other centres’, that seemed to me to be a role for the national network, but they weren’t resourced to do it.”*

Regional Network Co-ordinator

There is clearly a role for the UKNSCN in helping to provide a unified face for UK stem cell science to the outside world. However, feedback from stakeholders suggests that the organisation is not currently sufficiently resourced to fulfil this role.

### **3.3.3 Summary**

Although the UK has a strong position in stem cell research, science in the twenty first century is a global endeavour, and it is important that the UK has strong international partnerships at both a research and a commercial level. We have found clear evidence that there would be a benefit to stem cell research in the UK if an organisation was to fulfil the objective of being a focal point for overseas researchers. This is reflected in the importance placed on there being an organisation to fulfil this role by stakeholders and respondents based overseas.

Regional networks provide good detailed information about activities, facilities and capabilities within their area, but they cannot provide a ‘one stop shop’ for enquiries about the UK, and some areas of the UK (including those containing important research groups) are not covered by active regional networks. Furthermore, the plethora of regional networks gives a confusing profile of the UK to the international stem cell community.

As a UK-wide organisation with connections to the research base, the UKNSCN has the potential to be an information hub for UK stem cell science for the outside world. The UKNSCN has clearly made a start on fulfilling this objective, and is visible on the international scene. Despite this, the continuing high profile of regional networks internationally continues to give the impression of a fragmented UK stem cell community. There is also evidence that the UKNSCN is not sufficiently well resourced to provide the range of services that would be most useful to overseas partners at this stage.



## 4 Influencing objectives

Recommendation 10 of the Pattison report suggested that “*The Cooperative should also work with the International Stem Cell Forum on the characterisation of stem cell lines, the ethical landscape and intellectual property issues*”. This implies a broader role than that described by the networking objectives we examined in Chapter 3. During the 2006 Town Meeting, it was decided that the UKNSCN should adopt objectives to provide the voice of the community in two arenas: to the media and the public; and to regulators and policy-makers.

This chapter discusses each of these ‘influencing’ objectives in turn, discussing first the evidence that there is a need in the community for an organisation to address the objective, and secondly the performance of the UKNSCN in doing so to date.

### 4.1 *The national focal point for communication with the media and the public*

#### 4.1.1 Rationale for objective and evidence of demand

The UKNSCN aims to be *the national focal point for communication with the media and the public*. Stem cell research is a high-profile area of science, and recent events such as the Human Fertilization and Embryology Bill 2008, and the successful transplant of a trachea using tissue grown from the patient’s stem cells in November 2008, provoked great media interest.

Many respondents suggested to us that the extent of media interest presents potential problems for the science. In particular, several respondents reported that if public expectations for what can be achieved in the short and medium term are too high, public support for stem cell science may turn to disillusionment. In this view, the network could play a role in moderating public expectations through the media. Another commonly expressed view was that:

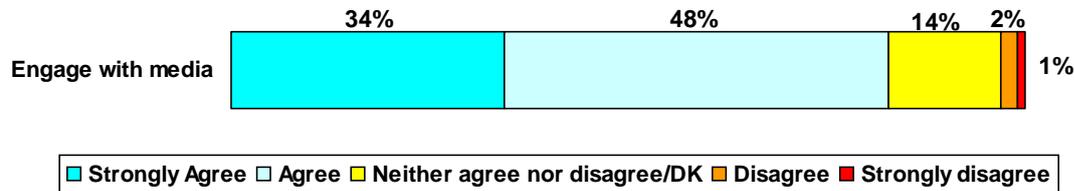
*“I think the public needs to be taken along on this journey with us. I mean we can’t just at the end of the day come out and say ‘well we’ve got a stem cell therapy’ and the public is horrified by how they’ve actually got that therapy, or do not understand it, or it’s misrepresented. I think there’s a role for the UK stem cell network to make sure that the information is out there and that the information is accurate.”*

Commercial scientist

Most of those who responded to our on-line questionnaire (90%) agreed that it is important that there is a focal point for communication between the UK stem cell community, the media and the public, and a majority of respondents (82%) agreed that it would be helpful to them if the UKNSCN engaged with the media to get messages to the public (as shown in figure 4.1).



**Figure 4.1: It would be helpful to me if the UKNSCN were to... further engage with the media to get key messages to the public**



Base: All who answered (359)

However, interviews with journalists and others revealed that the media itself does not see a need for any organisation to be ‘a focal point’. This is in part because of the large number of talented communicators that journalists are already able to call upon within the stem cell research community:

*“I would say that [there is a role for a focal point] if I thought journalists were struggling to get scientists when they need them, but I don’t think they are. So many of the stem cell scientists are brilliant communicators, and believe that they should communicate, so there isn’t a problem.”*

Journalist

This view was also given by some scientists who regularly speak to journalists:

*“The press knew us very well before the UKNSCN. They’re always going to ring us, they have our home numbers. Just because there is a UK network doesn’t mean that the press will change their habits. They want to know what is going out on the Today programme at 6am, they are going to ring us at 4am, because they know we will give an answer, and they trust us. They know we have done a good job for a long time.”*

Stem cell researcher

Whilst there may not be a role for the UKNSCN as a focal point for the media, there is still a potential role in providing resources for journalists, and perhaps more importantly for the public:

*“The public have more often than not got better things to do than engage with scientists. They want to know about these things when it affects them more directly, so when a family member becomes ill, and anything they [UKNSCN] can do to provide resources, particularly online resources, as to what can, and more importantly can’t, be done at this stage with stem cell treatments would be useful.”*

Journalist

#### 4.1.2 Performance

UKNSCN activities to support communication with the public and the media include:

- Development of a media strategy in close liaison with the Science Media Centre
- Newsletters in hardcopy or as downloads from website
- Fielding enquiries from the general public about availability of stem cell therapies



The UKNSCN has been able to make use of the BBSRC press office, and therefore the existing BBSRC media experience and contacts with high level journalists. Journalists have been positive about the role played by the BBSRC press officer:

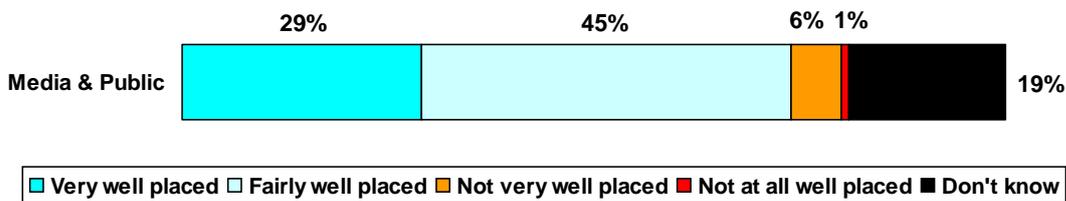
*“He is good in that he makes you aware of things that you are likely find interesting, without having unreasonable expectations of what I’m likely to get into the paper, or hassling me unduly about things that probably aren’t going to be newsworthy. So I think it is a pretty effective operation.”*

Journalist

Through the BBSRC press officer, the UKNSCN has been able to establish links with an important intermediary in the science field, the Science Media Centre (SMC), and UKNSCN briefings have been held with the SMC. As a result of these arrangements, the UKNSCN is able to access key figures in the media when it has a newsworthy story.

However, this is not the same as being a ‘focal point’, and as demonstrated in the preceding section, the media do not necessarily feel the need for a ‘focal point’ for stem cell science. Despite this, a majority (74%) of respondents to the online questionnaire thought that the UKNSCN was well placed to fulfil this role.

**Figure 4.2: How well placed the UKNSCN is to be the national focal point for communication with the media and the public**



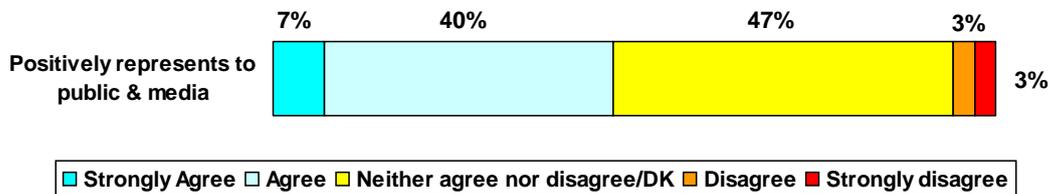
Base: All who answered that it is important to have a focal point for the media and the public (320)

Those who said that the UKNSCN is ‘very well placed’ emphasised that it has national reach, that it reaches across the different interests and disciplines involved, and has the involvement of leading stem cell scientists. Those who said it is ‘fairly well placed’ qualified such views by suggesting that the UKNSCN could have a higher profile, or that there are various voices in the stem cell field and one organisation cannot aspire to represent them all.

However, as shown in figure 4.3, there was a less positive response from respondents when asked whether they agreed that ‘the UKNSCN represents the UK stem cell community to the public and the media in a positive way’. Less than half of respondents agreed that the UKNSCN does this, and only 7% of respondents strongly agreed. This reflects the relatively low profile that the UKNSCN has had in this area to date.



**Figure 4.3: Does the UKNSCN represent the UK stem cell community to the public and the media in a positive way?**



Base: All who answered (353)

Some of those we interviewed indicated that they were surprised that there was not more information available to the public on the UKNSCN website:

*“I would have expected there to be more information on the website to enable members of the public to make an informed judgement about, for example, what are cytoplasmic hybrids, why are they important, what about transgenics, a simple guide through what those were.”*

Stakeholder

### 4.1.3 Summary

The evidence we have presented shows that there is not a role for a ‘focal point’ for communication with the media; not least because the media do not require it. Nevertheless, there is an evident desire among respondents for the UKNSCN to have a media role. Favourable public opinion is of great importance if this rapidly developing field is to continue to have a favourable regulatory environment in the UK. Many members of the community articulated a need for a credible UK wide organisation to provide resources on subjects of particular interest directly to the public, and to be able to disseminate information and messages on behalf of the community.

The UKNSCN has had the advantage of access to a press officer who is respected by science correspondents. The constructive relationship that has been established with the Science Media Centre is a model of the way in which the UKNSCN should work with external organisations to maximise its impact with limited resources. The UKNSCN delivery plan indicates that information will be provided for the public. As an organisation with connections to important research funding bodies, and a UK wide remit, the UKNSCN is in a good position to provide authoritative online resources about subjects such as stem cell tourism direct to the public.

## 4.2 The national voice of the stem cell community to policy makers and regulators

### 4.2.1 Rationale for objective and evidence of demand

The UKNSCN also aims to be *the national voice of the stem cell community to policy makers and regulators*. The HFE Act 2008 demonstrated the importance of regulation in influencing the science that can be performed in this emerging field. Most of those who responded to our online questionnaire considered this role to be very important (61%) or fairly important (32%).



The geographical specificity of the regional networks was felt to limit their effectiveness in this area. One member of a regional network underlined the importance of having influence at a national level in order to achieve appropriate regulation that can allow science to flourish:

*“This is about international competitiveness as much as anything else. From a regional view, we want to have the best stem cell and regenerative centre in the world here. To achieve that, it is no good changing a few local byelaws.”*

Member of a regional network

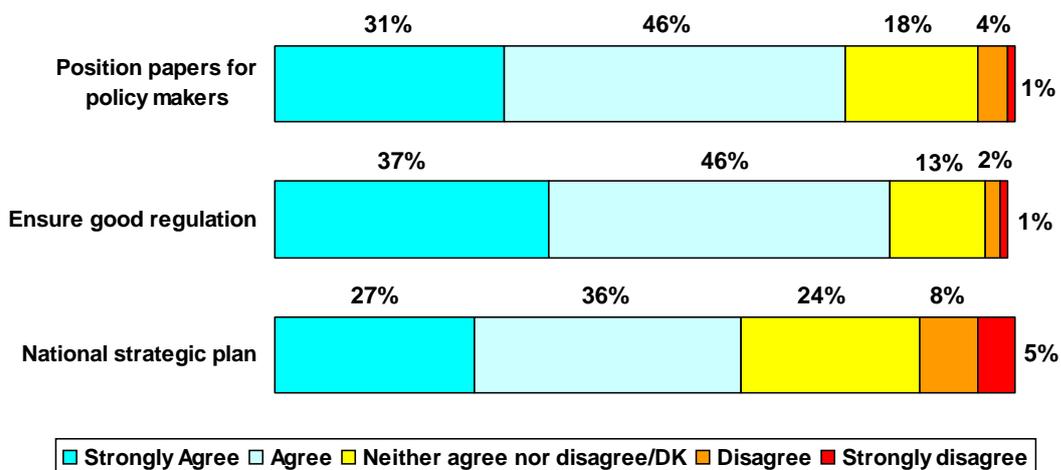
Some respondents also felt that it was important to have an organisation that could assist companies in their interactions with regulators to promote the translation of stem cell therapies on a larger scale:

*“If you are in this slight grey zone where you are an organisation that recognises that you have to develop some kind of quality assurance or quality control assays, and if it is unclear who is going to fund those, how are the regulators going to take these forward? There isn’t a focal point to bring these together.”*

Consultant

In its corporate plan the UKNSCN has proposed activities to influence policy makers and regulators. Our online questionnaire asked how helpful activities proposed by the UKNSCN would be, and responses are shown in Figure 4.4 below. Most respondents (77%) agreed that it would help them if the UKNSCN produced position papers for policy makers. A larger proportion (83%) felt that the network working closely with the relevant bodies to ensure appropriate regulation of stem cell science would be helpful to them. Fewer respondents thought that the development by the UKNSCN of a national strategic plan for UK stem cell science extending to 2015 would be of benefit to them. Even so, a majority (63%) did agree that the UKNSCN should develop a national strategic plan.

**Figure 4.4: How helpful proposed activities towards policy makers and regulators would be**



Base: All who answered (358) (355) (359)

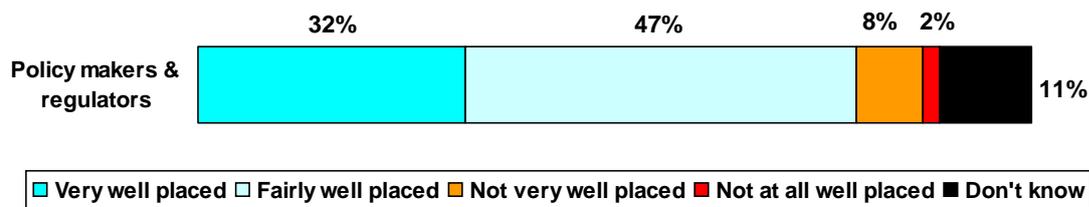


### 4.2.2 Performance

The UKNSCN has had the advantage of a direct voice in Parliament through its chairman, Lord Patel. The network has sought to provide a voice to regulators and policy makers through the following activities:

- Production of a review of the delivery of the Pattison report recommendations, which was discussed with senior decision makers in science funding in relation to the 2007 comprehensive spending review
- Nine page written briefing for House of Lords in advance of debate on stem cell research on 3 May 2007
- Evidence submitted to four public consultations
- Steering committee meeting with representatives of patient groups and charitable organisations to discuss collaborative activities
- Steering committee meeting to discuss on-going regulatory issues holding back the progress of UK stem cell research

**Figure 4.5: How well placed is the UKNSCN to be the national voice of the UK stem cell community to policy makers and regulators?**



Base: All UK-based respondents who thought that it is an important role, and answered (263)

Most (79%) of UK based respondents thought that the UKNSCN is well placed to be the voice to policy makers and regulators. Those who said that the network is ‘very well placed’ gave reasons relating to the national reach of the UKNSCN, and the credentials of its membership:

*“The organisation consists of experts in the fields of developmental biology, cell biology, embryology and stem cell science. This multidisciplinary network can give a broader perspective.”*

Academic researcher

*“To my knowledge it is the only national voice in the UK of the stem cell community.”*

Academic researcher

Those who said that the network was ‘fairly well placed’ qualified their comments by saying that the network was not very well established yet, or that it does not yet represent all of the voices and interests in the stem cell field. Some respondents also questioned whether it was possible for a single organisation to represent, for instance, the interests of the research base as well as commerce. In addition, some suggested that the UKNSCN is not transparent or fully representative:

*“Not all the stem cell work that is being done in the UK is represented.”*

Academic researcher



*“While it has strong connections with the academic community, it lacks connection with the commercial community. Moreover it is doubtful that both can/should be represented by the same voice.”*

Commercial researcher

*“Although the organisation is doing good work, management is not totally clear and it seems to me too centralized.”*

Academic researcher

*“The decisions about board membership and the activities of the board seem not very democratic nor transparent. More influence on what the Network does in its public and policy engagement and how it does that might benefit both its acceptance in the community as a representative speaker and its influence and success.”*

Academic researcher

Several interviewees we spoke to recognised the advantage that the network held in having a Chairman who sits in the House of Lords.

*“Persuasion has to go all the way up. And the point is that the UK national network is chaired by Lord Patel so you can imagine that there’s no better voice-box.”*

Stakeholder

As Chairman of the network, Lord Patel spoke on behalf of stem cell science during the House of Lords debate he organised on the 3<sup>rd</sup> May 2007, and also spoke in Parliament on matters regarding the HFE Act in 2008. The Parliamentary activity has been recognised as useful by some stakeholders:

*“[The UKNSCN] played an important role in lobbying around the HFE bill. And they also did create some movement around the regulation process... [for] the governance of embryonic stem cells..”*

Policy Stakeholder

Nevertheless, relying on the presence of a high profile UKNSCN member who is also a Parliamentarian is not a sustainable way to influence policy. Despite UKNSCN activity in the policy and regulatory field, most stakeholders we interviewed who hold policy roles did not consider that the network has made a leading contribution in this area to date. Several stakeholders mentioned the debate surrounding the HFE Act earlier this year as one in which the UKNSCN may have been expected to be more visible:

*“Various groups, the Wellcome Trust, the MRC, the SMC and Evan Harris, they formed their own informal network to try to get the bill changed and to get it through in the form they thought best. And I didn’t really see much of the hand of the stem cell network in that.”*

Journalist

Another stakeholder described the Wellcome Trust and the MRC as playing a leadership role in a coalition of organisations that contributed to legislation. Although the UKNSCN



added its voice to the debate, it was not considered to have played a central role. Even so, its contribution was thought to be constructive:

*“We’ve all been influential, and we’ve been influential by working collaboratively, and by making sure that policy makers hear the same message from lots of different sources.”*

Policy Stakeholder

It should be noted that much of the UKNSCN activity in regard to the HFE Act involved activities such as the briefing of many Members of Parliament, and these briefings by their nature may have been influential without having been visible.

The UKNSCN has proposed the development of policy and regulation influencing activities over the period described in the three year corporate plan and the one year delivery plan. Among these is the development of ‘a national Strategic Plan for UK stem cell science which delivers what will be necessary to realise the Government’s 10-year vision for stem cell research extending to 2015’<sup>4</sup>.

Our discussions with policy stakeholders indicate that they do not feel that the UKNSCN is yet in a position to contribute to policy-making at a strategic level. In particular, several respondents held the perception that policy or strategy documents produced by the UKNSCN reflected the views of the steering committee, rather than the views of the stem cell community as a whole. This was thought to reduce the value that the UKNSCN perspective can add to decision making.

*“I haven’t seen it strongly so far that they bring the messages back up from the academic base or from the community in saying what they think is going to be important.”*

Policy Stakeholder

This view was reinforced by another stakeholder:

*“It is driven by the steering committee. I have never had a sense that they have consulted their network in lots of depth or detail or even breadth, and that they speak with authority about those views. I think they could do more to be representative or to show that they are representative of this very large community... Apart from Lord Patel, I don’t have in my mind a group of scientists who are members of the network and who speak on behalf of them in that way. I think that absence reduces their authority.”*

Policy Stakeholder

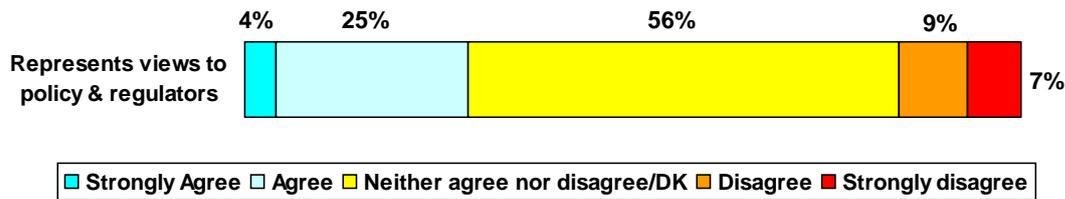
Figure 4.6 supports the views that interviewees expressed about the lack of consultation with, or representation of, the UK stem cell community. Most UK based respondents do not agree that the UKNSCN represents their views to policy makers and regulators.

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<sup>4</sup> [http://www.uknscn.org/downloads/pdfs/delivery\\_plan.pdf](http://www.uknscn.org/downloads/pdfs/delivery_plan.pdf)



**Figure 4.6: The UKNSCN represents my views to policy makers and regulators**



Base: All based in the UK who answered (282)

15% of UK based respondents said that they had contributed views to the UKNSCN about issues pertinent to public consultations, and the UKNSCN does canvass for contributions. Nevertheless, the finding shown in Figure 4.6, and the perceptions of decision makers and other workers in the policy sphere suggest that the UKNSCN is not perceived as consultative or representative by members of the stem cell community or policy makers.

Some interviewees suggested that the network was an effective channel for the dissemination of information to the stem cell community. However, this was not felt to be sufficient to give the UKNSCN a valued voice in policy formation. Were the network seen to be more consultative, and less reflective of only the views of the steering committee, it could have a larger role to play in strategy and policy development:

*“I think this is the problem of the steering committee control of the network... if the network was adding value on the ground, it would naturally have a voice and a role in strategy. So I think it is a bit of the cart in front of the horse.”*

Policy Stakeholder

These views strongly suggest that if the UKNSCN is seen to have established an extensive network within the stem cell community that it can consult, and can therefore represent, policy-makers will be more likely to take account of information and perspectives provided by it when making decisions.

Some stakeholders are concerned that because the UKNSCN is funded by, and located within, the Research Councils, it may be perceived as lacking independence or effectiveness in speaking on behalf of the stem cell community. From interviews with a range of key stakeholders, and our online questionnaire with members of the community, this seems to be a minority view. Contrary to this, many interviewees considered this to be a strength, because of the central role that public funding plays in stem cell research at this time. Being associated with the research funders was thought to be beneficial because it represents connections with these influential bodies. Furthermore, several interviewees saw this as a source of independence, interpreted as independence from:

- regional networks, and the Regional Development Agencies;
- private companies, who may be influenced by adverse public sentiment (especially overseas) towards embryonic stem cell research; and
- central government.

The main argument some stakeholders made for independence from the Research Councils is that the UKNSCN would be more able to publicly lobby for funding for stem cell research. However, we do not feel that this is persuasive. The UKNSCN’s



relationship to the Research Councils means that it is able to present arguments on behalf of the stem cell community directly to decision makers. Whilst this may be less visible than public lobbying, there is no reason to think it is less effective.

### 4.2.3 Summary

Several stakeholders cited the favourable regulatory environment of the UK as key to the current strength of UK stem cell science. Nine out of ten respondents to the online questionnaire agreed that it is important for an organisation to provide a voice for the community to policy-makers and regulators, and more than eight out of ten agreed that it would be helpful to them if the UKNSCN was to work to ensure appropriate regulation. Again, although members of regional networks may play a role in policy and regulatory work, this is an obvious remit for a UK wide organisation such as the UKNSCN.

The UKNSCN played a role in lobbying for the HFE act, and was assisted by having Lord Patel as chairman, able to speak directly in Parliament. However, it did not play a leading role in influencing the legislation, and cannot count on having a chair with a direct voice in Parliament in future. Furthermore, this voice does not *necessarily* represent 'the voice of the community'. There is a perception among stakeholders that the UKNSCN is representative of the steering group, but does not consult sufficiently with the community. This view seems to be reinforced by evidence from the online questionnaire, with only three out of ten respondents agreeing that the UKNSCN represents them to policy makers or regulators. Policy stakeholders expressed some scepticism that the UKNSCN could play a role in policy or strategy development as it currently operates, but said that the network would be able to play a useful role in future if it was seen to be a more consultative body.

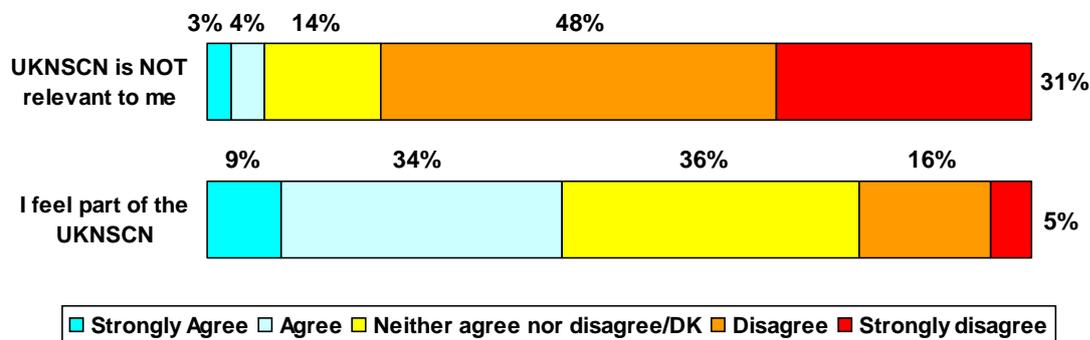


## 5 Relationship with the Community

The preceding chapter has raised questions about the nature of the relationship between the UKNSCN and the stem cell community. This relationship is of vital importance if the UKNSCN is to serve as a national focal point for communication with the media and the public, or as a national voice to policy makers and regulators. We have seen that policy stakeholders, in particular, feel that the UKNSCN would have more to contribute if it actively consulted the stem cell community.

Respondents to the online questionnaire were asked about their relationship to the network. Figure 5.1 below shows their response to two questions.

**Figure 5.1: Relationship between the UKNSCN and the stem cell community**



Base: All UK based respondents who answered (277) (281)

Respondents to the survey clearly feel that the UKNSCN is relevant to them. Four out of five (80%) UK based respondents *disagreed* that ‘The UKNSCN is NOT relevant to me’. However, this does not indicate that they felt closely associated with, or a part of, the network. Just over four in ten UK based respondents (43%) agreed that ‘I feel that I am a part of the UK National Stem Cell Network’, and only one in ten respondents (9%) strongly agreed.

This suggests that the UK stem cell community does not (yet) feel that it has ownership of the UKNSCN. This is likely to reflect the concerns that we have seen in the preceding sections about the network being driven primarily by the steering group and not being perceived as transparent or sufficiently consultative by a wide range of stakeholders.

Some respondents and stakeholders mentioned that in their view the UKNSCN is more focussed on embryonic stem cell research than on adult stem cell work. The online questionnaire was analysed for difference in attitude to the UKNSCN between two groups;

- those who were interested in adult stem cells but not embryonic stem (ES) cells; and
- those who were interested in ES cells, but not adult stem cells.

Our results show that on most issues there was no difference in responses between these groups (although in some cases those who are interested in adult stem cells appear to be more positive toward the UKNSCN). This implies that there is not a widespread perception that the UKNSCN is biased in this regard.



Feedback about the network co-ordinator was positive. He provides a visible presence for the UKNSCN at meetings and respondents to the online questionnaire mentioned meeting him, or that he had been very helpful in providing them with contacts or information. Feedback from stakeholders was also positive:

*“I think you need someone who is lean and mean and who is out there and aware of what is going on. And I think that is what [the co-ordinator] is doing. He is around a lot, he is plugged in.”*

Policy stakeholder

Some stakeholders we spoke to suggested that the UKNSCN has not tended to forge relevant connections with other organisations in relation to discharging its objectives, and have described it as “*isolated*”.

Recommendation 10 of the Pattison Report was motivated by the need for an organisation to do at a UK level what the regional networks have achieved at a regional level. Therefore the relationship of the UKNSCN with the regional networks is of special importance, and the UKNSCN recognises this. UKNSCN press releases describe the organisation as “*a network of the existing regional stem cell networks in the UK, to bring coordination and coherence to a range of national and regional activities in the field of stem cell research*”.

Although this is a key area, co-ordination with the regional networks does not seem to have been achieved to a significant degree. Members of the regional networks that we spoke to said that they felt the UKNSCN did not have a clearly defined role and was not transparent about its activities to the extent that they could plan their activities with confidence that there would not be duplication. One member of a regional network told us:

*“I think we do need clarity over and above the top line statements. You know, we need evidence to actually support the claims that they make in terms of what they do... It’s so important that there’s clarity because if we go off and do things that other networks are doing then that’s a waste of tax payers’ money.”*

Regional network co-ordinator

The clarity of the role of the UKNSCN is also important in establishing relationships with other organisations. One stakeholder explained how clarity of role is essential for the effective provision of information to the commercial sector:

*“One of the biggest challenges is that you’ve got Government departments, Research Councils and other funding bodies going and talking to businesses, and the businesses are getting confused because they are not sure how we relate to each other. So it is making sure that you have the landscape, and you see where the UKNSCN sits, and then you see where everybody else sits relative to each other, and have an agreement when to signpost people to particular organisations.”*

Policy Stakeholder



Many interviewees recognised that the network has been in operation for less than two years and has not yet had time to build all the relationships and connections that it should. It is of vital importance for the UKNSCN to build strong relationships with other organisations in the future if it is to be effective in achieving the objectives that it has been set.

### **5.1 Summary**

Responses to the online questionnaire show that most members of the community do not tend to feel strongly attached to the UKNSCN. This is in line with evidence that the UKNSCN is thought to be more reflective of the views of the steering committee than of the community.

Furthermore, some stakeholders consider the UKNSCN to be lacking in transparency, and not to have built strong relationships with other relevant organisations in the stem cell field. These are areas that the network can build on in its next period of operation.



## 6 Conclusions

The evidence that we have gathered shows that there is a role for an organisation to pursue both the networking and influencing objectives for the UK stem cell community. The UKNSCN has not yet been able to fully fulfil these objectives. However, the first steering committee meeting was held in December 2006, and two years of operation have provided a good foundation on which to build.

There is more that the UKNSCN can do. In particular, we have found strong evidence that although the UKNSCN was established to fulfil the role of a network, it is perceived by many to be a committee. Although many connections have been made, the stem cell community has yet to develop strong feelings of ownership of the network. This lack of development as a network also adversely affects the ability of the UKNSCN to fulfil 'influencing' roles. To be able to act effectively as the 'voice' of the stem cell community, the UKNSCN needs to have the legitimacy and authority that comes from representing a network with roots in the community. In turn, for the network to engage fully with members of the community, it needs to offer them something in return, such as speaking for them to policy makers, regulators, and the public. These relationships will take time to develop.

To improve its effectiveness with the limited resources at its disposal the UKNSCN needs to focus strongly on developing its capacity to fulfil the 'networking' objectives, those which are closest to the role outlined in recommendation 10 of the Pattison Report. Above all, this requires the co-ordinator to have the resources and decision making ability to function as a hub, able to organise events and distribute information among the many interested bodies in the stem cell field. In addition, the co-ordinator needs strong strategic direction from organisations (not just individuals) that are significant within the UK stem cell environment, but tactical freedom to deliver within the strategy.



## 7 Recommendations

### 7.1 Focus of the network

The central role of the network should be to facilitate the exchange of information between different people and groups in the stem cell field at a UK level. The evidence we have collected shows that until the UKNSCN can function effectively as a network, and can demonstrate that it is in touch with the concerns of the various parties involved in UK stem cell science, it can only play a limited role in policy formation. Development of the networking roles of the UKNSCN should therefore take precedence over the influencing roles.

The kind of activities the network should focus on include:

- acting as a port of call for enquiries about stem cell science in the UK, from UK-based and overseas enquirers;
- providing online resources, such as a web-based directory of expertise;
- maintaining an extensive network of contacts based in the UK and overseas;
- disseminating information about events and opportunities through an e-mail bulletin;
- organising the annual meeting; and
- organising other networking events.

This recommendation is not meant to preclude other activities where there is a strong case for the network to undertake them, or where it is particularly expedient for the network to do so. The network may decide to provide online resources for the public, and advice to policy makers where appropriate. However, the main thrust of activity should be towards enhancement of the UKNSCN's networking role.

**Recommendation 1:** The UKNSCN should re-focus its objectives to prioritise its networking role.

### 7.2 Staff resources

A network requires a hub to enable and support the exchange of information, as well as to act as a repository of knowledge of community activities. The networking activities set out in section 7.1 can be enhanced if effectively co-ordinated. A co-ordination role should facilitate information exchange and help people to make the appropriate connections. This relationship is shown in figure 7.1 on the next page. Such a co-ordinator would then also be well placed to conduct some influencing activities, such as connecting journalists with particular researchers, and providing authoritative online resources for the public.

The co-ordination function is currently carried out by one full-time member of staff. This is in stark contrast to the co-ordination activities of regional networks, which employ up to three full-time staff members. We have seen evidence that the demand for information from the UKNSCN exceeds its ability to provide such information at present. More than one full-time member of staff should be employed if the UKNSCN is to perform the range of tasks required to fulfil its networking function effectively.



**Figure 7.1: Information exchange and dissemination via the network co-ordinator**

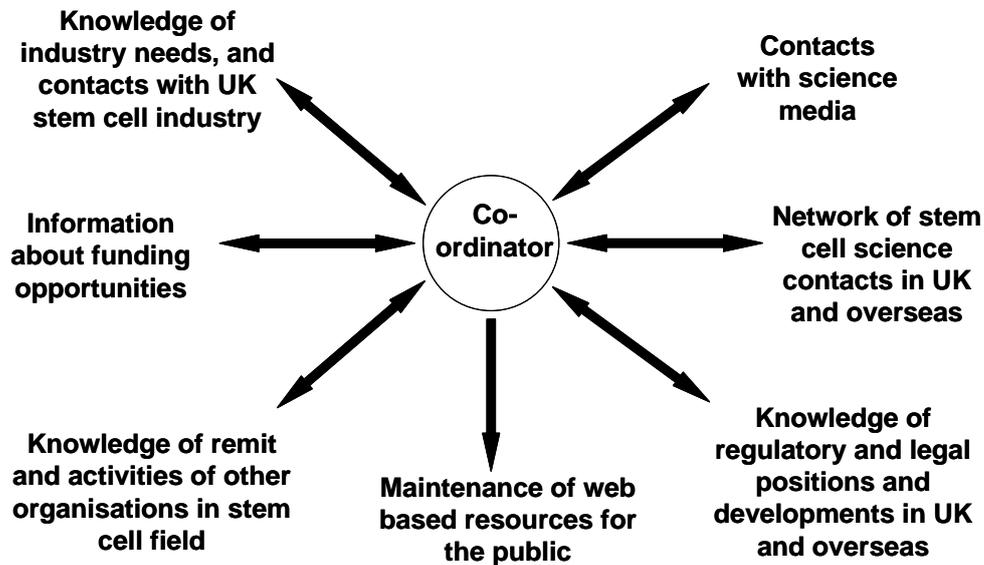


Figure 7.1 demonstrates the importance of the co-ordinators role as a repository for and disseminator of information and knowledge between the different parties involved in stem cell science. However, the main purpose of the network hub should be to stimulate interaction between industry, academia, clinicians, the public, policy-makers, regulators, lawyers and ethicists. In the longer term the aim should be to encourage decentralised interactions between these groups, not controlled by a central point.

**Recommendation 2:** The UKNSCN should appoint at least one more full-time member of staff to enhance its networking capacity.

### **7.3 Corporate structure**

The UKNSCN one year plan gives five possibilities for the future development of the network:

- Industry/trade association
- Public-private partnership
- Learned society
- Not-for-profit company limited by guarantee
- No change

Evidence from stakeholders suggests that the UKNSCN does not have strong enough links in the business community to operate as an Industry or Trade Association.

Many stakeholders expressed concerns that direct commercial funding, even as part of a public-private partnership, would prejudice perceptions of the independence of the UKNSCN. For this reason, we believe that a public-private partnership is not an appropriate model for the UKNSCN at this stage.

We have not found a strong demand among interviewees for a Learned Society in the stem cell field at this point, and also do not think that a subscription funded model would



generate sufficient funding or membership at this point in the UKNSCN's development. The online survey provides evidence that members of the community do not currently feel a strong sense of attachment to the network. If the UKNSCN successfully cultivates a sense of ownership among members of the stem cell community in future, developing as a learned society may become a possibility. Any such society would need to be inclusive of the wide range of different parties involved in the stem cell field if it were to contribute towards achievement of the current objectives of the UKNSCN. It is important to recognise the current moves towards consolidation in the field of biology, with the Institute of Biology and the Biosciences Federation in discussions about the creation of a single organisation to represent biology.

The most active regional networks are established as not-for-profit companies. This model has several advantages. The regional networks enjoy the direction of a board, which includes representatives of the network funding bodies, who are able to ensure that the network has a clear remit and that the organisation is achieving its aims, and who are able to bring the executive to account. This focus is combined with day-to-day independence for the executive, so that it is free to achieve the aims of the network. The regional networks typically also have a scientific advisory board that they can consult, and from which they can draw to organise working groups when necessary.

This model adopted by these active regional networks is clearly effective. However, at present the UKNSCN has a wide remit and limited resources. The in-kind contributions that it receives from BBSRC, including physical hosting and access to an experienced press officer, are of substantial value. We do not recommend that the UKNSCN becomes an organisation independent of the Research Councils if it would mean losing access to these resources, unless similar cash or in-kind contributions are available.

**Recommendation 3:** The UKNSCN should continue to be hosted by the Research Councils.

## **7.4 Governance**

The network has a role to play within the existing institutions that serve UK stem cell science. To fulfil its activities it must work with the other significant organisations in the field to ensure that resources are used most efficiently.

The direction of the network should be set by those with connections to and knowledge of the activities of the other organisations who are providing information and networking services in the Stem Cell field. Governance of the network by those with such breadth of strategic vision would help to minimise duplication of the activities of other organisations. It would also enable the UKNSCN to know more about and use sources of expertise, knowledge and resource in external organisations. Organisations such as the Technology Strategy Board, DIUS, and the MRC administer or sponsor bodies with remits that touch upon that of the UKNSCN, and with whom the UKNSCN should build stronger links. By avoiding duplication and finding synergies with other organisations, the UKNSCN could act more effectively and ensure that it provides better value for money to the UK taxpayer. We therefore recommend that the UKNSCN should be governed by a management board comprised of representatives of the funders of the network.

The network should forge connections across the UK stem cell community including researchers, clinicians and industry, but as currently constituted it is perceived by some as



more representative of the research base. This limits its ability to fulfil its potential as an organisation that can support the translation of UK stem cell science into therapies. We recommend that the Research Councils should invite other non-commercial organisations to contribute funding to the network, and to sit on its management board. This would enable essential roles, such as its relationship to business at home and overseas, to be clarified with regards to other bodies operating in this field. Potential funders include the Department of Health, DIUS, the Wellcome Trust and other charities. The UKNSCN also needs a better connection to the commercial sector. Recognising the concerns about direct commercial funding, we therefore recommend that the Technology Strategy Board (TSB) also be approached to contribute funding and sit on the management board. We expect that this relationship ensure that the TSB's extensive knowledge of and contacts with UK industry can help to inform the UKNSCN's strategy.

This report has shown that many in the Stem Cell community believe that the UKNSCN has an important role to play in promoting the development of UK stem cell science, alongside other organisations in this field. The management board should ensure that the direction of the UKNSCN is set to enable it to do this. As a body comprised of the funders of the UKNSCN the board should ensure accountability for expenditure, and should therefore govern the activities of the co-ordinator.

**Recommendation 4:** A management board should be established to direct the network, and other public and charitable bodies active in the stem cell field should be invited to contribute funding to the UKNSCN and thus qualify to sit on the board.

## **7.5 Advisory support**

It is essential that the UKNSCN remains closely connected with key figures in the stem cell community. The steering committee (as currently constituted) should play an advisory role, becoming an advisory committee to the network. It should offer advice about the management and direction of the network, with the Chair of the advisory committee invited to join the management board of the UKNSCN. In addition, the committee should play a role in enabling the UKNSCN to connect with, and reflect the views of, the stem cell community. This should involve supporting working groups comprised of members of the community, advising on consultative and networking activities, and other activities as decided by the UKNSCN. The management board of the UKNSCN should decide under which conditions the Expert Committee should meet, subject to the requirement that acting as secretariat to committee should not place a burden on the UKNSCN co-ordinators.

**Recommendation 5:** The role of the steering committee should be modified so that it plays a strong advisory role. The chair of this Expert Advisory Committee should be invited to join the UKNSCN management board.



## Technical Appendix

### *Online questionnaire*

#### **Questionnaire development**

The questionnaire used for the online survey was developed by PSP. It asked for views on the need for an organisation to fulfil the objectives of the UKNSCN, the respondent's experience of involvement with the UKNSCN, views on proposed future activities, and thoughts on the future development of the network. Most of the questions were multiple choice, and automatic routing ensured that only relevant questions were asked. Where appropriate, questions also allowed free text responses.

Seventeen members of the stem cell community were invited to take part in the pilot. Two completed the pilot questionnaire, and researchers from PSP interviewed them to assess whether the questionnaire could be improved. After minor comments from pilot respondents the final version was approved by BBSRC.

#### **Sample**

Invitations to take part in the online questionnaire were sent to everyone on the UKNSCN mailing list. The list contains people with an interest in stem cell research from a variety of disciplines, based both in the UK and overseas. Therefore although the sample for the questionnaire has broad reach across a range of people who are aware of the UKNSCN, it is not statistically representative of all of those with an interest in UK stem cell science. PSP removed duplicate entries, and those who had been approached to take part in the survey as stakeholders or pilot respondents, from the e-mail list.

#### **Fieldwork**

Invitation e-mails were despatched to 1150 named individuals. A hyperlink to the online questionnaire which contained a unique ID was included with each e-mail. The ID ensured that only one questionnaire could be completed by each person invited to take part. This method also allowed respondents to save their responses part way through and re-access the questionnaire to complete it fully at a later time. When respondents completed questionnaires their ID was recorded so that they were excluded from reminder e-mails. The first e-mails were despatched on 22<sup>nd</sup> October 2008. Three reminder e-mails were issued, and last submissions were received on 28<sup>th</sup> November 2008. This represents a fieldwork period of more than five weeks.

#### **Survey response**

The invitation could not be delivered to 40 addresses. A further 31 people contacted us to tell us that they did not consider themselves to be eligible to take part as they did not work in a field related to stem cells and did not have a particular interest in the area. In total, there were 1079 addresses to which e-mails were delivered and who did not declare themselves to be ineligible.

Refusals to take part were received from 16 respondents. In addition, 90 respondents began to complete the questionnaire but abandoned it before completion. Data from these questionnaires has not been included in this report. Completed submissions were received from 362 individuals, including 286 based in the UK and 76 based overseas. As table A.1



below shows, this represents 34% of e-mail addresses that were assumed to belong to those eligible to take part. The average length of time taken to complete the questionnaire was 12 minutes.

The degree of attachment to the subject is generally an important factor that affects whether those who are invited to take part in a survey do so. PSP typically achieves response rates of 50% or more for e-mail surveys of those affiliated to the subject organisation. The lower response rate achieved for this survey may be partly due to the short length of time that the UKNSCN has been in existence, and suggests that many of those on the e-mail list have not yet developed strong ties to the UKNSCN.

**Table A.1: Survey response**

	<b>n</b>	<b>%</b>
<b>Total e-mail addresses</b>	1150	100%
<b>Undelivered</b>	40	3%
<b>Ineligible</b>	31	3%
<b>Sub-total (unknown eligibility)</b>	1079	94%
<b>Assumed eligible</b>	1079	100%
<b>Refused</b>	16	1%
<b>Abandoned</b>	90	8%
<b>Other non-response</b>	611	57%
<b>Complete</b>	362	<b>34%</b>

### **Respondent Profile**

The online questionnaire captured the views of one in three of those on the mailing list, drawn from all of areas of the stem cell community. Table A.2 shows the profile of those who responded to the questionnaire, which reveals that the issues have been considered by parties with a range of different interests from both academia and elsewhere.

### **Analysis of Results**

Responses to the questionnaire were analysed using computerised cross-tabulations produced using SPSS software. The responses from those in the categories shown in table A.2 were analysed separately, but in general there were not strong differences between different groups. Where there are meaningful differences these are discussed in the text of the report.

**Table A.2: Profile of Respondents<sup>5</sup>**

		<b>n</b>	<b>%</b>
<b>Total</b>		362	100%
<b>Sector</b>	Academia	221	61%
	Not academia	139	38%
<b>Seniority</b>	Senior	137	38%
	Not senior	199	55%
<b>Location</b>	UK	286	79%
	Overseas	76	21%
<b>Area of Interest</b>	Adult stem cells	252	70%
	Embryonic stem cells	221	61%
	Translational medicine	201	56%
	Clinical application	163	45%
	Bio-processing	72	20%
	Law/ Regulation	98	27%
	Social science	44	12%

### ***In-depth interviews***

In total, 37 in-depth interviews were conducted as part of this review. Interviews followed a topic guide that contained the key issues to be raised with the respondent. Most interviews were recorded so that transcriptions could be made, although in a few case contemporaneous notes were taken. Stakeholders chosen for interview represented a wide range of interested bodies, and the type of respondents interviewed are shown in Table A.3 below. Interviewees were not chosen to be representative of the stem cell community, but because they represented organisations or perspectives that are highly relevant to the activities of the UKNSCN.

**Table A.3: Profile of Stakeholders**

	<b>n</b>
<b>Total</b>	37
<b>Policy stakeholders</b>	7
<b>Academic researchers</b>	8
<b>Commercial scientists</b>	3
<b>Lawyers/Consultants</b>	2
<b>Research Charities</b>	2
<b>Journalists</b>	3
<b>Network co-ordinators</b>	5
<b>UKNSCN staff</b>	2
<b>UKNSCN steering committee</b>	5

<sup>5</sup> Respondents were not forced to answer all questions so percentages do not add to 100. More than one option could be chosen for area of interest.



Stakeholders for interview were chosen by PSP, after taking into account some suggestions from BBSRC and the steering committee members. Some stakeholders were chosen as a result of responses submitted to the online questionnaire that presented interesting perspectives requiring further discussion.



## Online Questionnaire Text

**KEY:** SC = Single Code; MC = Multi-Code;  
X = exclusive code for MC question

### Review of the UK National Stem Cell Network

This consultation forms part of a review of the UK National Stem Cell Network (UKNSCN), which People Science and Policy Ltd are conducting on behalf of the Biotechnology and Biological Sciences Research Council (BBSRC).

The review will assess the network's activity and role during its first two years of operation since 2006, and will make recommendations as to how it should develop in the future. This consultation asks about your involvement with the network, your views on how well it has fulfilled its role, and how it should develop to support you. If you have any queries about this work please call Alan Worley at PSP on 020 3102 8137.

The online consultation form is likely to take **about ten minutes** to complete depending on how many of the questions apply to you. If you want, you can save your responses using the button at the bottom of the screen, and re-access the questionnaire at a later time by clicking on the link in your invitation e-mail. If you need to go back to review your answers please use the back button at the bottom of the screen, as **using the back arrow on your browser will cause you to log out.**

Your responses will be treated confidentially. To view PSP's privacy policy click (opens as a new window in your browser).

**Q1 How long have you been aware of the UKNSCN?**

- SC
- Two years or more*
  - More than one year but less than two*
  - More than six months but less than a year*
  - Less than six months*
  - Only since receiving the e-mail inviting me to take part in this consultation*
  - Don't know*

ASK ALL

**Q2 How important is it to you that there is a national organisation speaking for the UK stem cell community to policy makers and regulators?**

- SC
- Very important*
  - Fairly important*
  - Not very important*
  - Not at all important*
  - Don't know*

[IF Q2=1 or Q2=2]

**Q3 In your view, how well placed is the UKNSCN to be the national voice of the UK stem cell community to policy makers and regulators?**

- SC
- Very well placed*
  - Fairly well placed*
  - Not very well placed*
  - Not at all well placed*
  - Don't know*



[IF Q3=1 or Q3=2 or Q3=3 or Q3=4]

**Q4 Please explain why you said the UKNSCN is '{text of answer from Q3}' to be the national voice of the UK stem cell community to policy makers and regulators?**

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ASK ALL

**Q5 How important is it to you that there is an organisation providing a focal point for communication between the UK stem cell community, the media and the public?**

- SC *Very important*
- Fairly important*
- Not very important*
- Not at all important*
- Don't know*

[IF Q5=1 OR Q5=2]

**Q6 In your view, how well placed is the UKNSCN to be the UK national focal point for communication with the media and the public?**

- SC *Very well placed*
- Fairly well placed*
- Not very well placed*
- Not at all well placed*
- Don't know*

[IF Q6=1 or Q6=2 or Q6=3 or Q6=4]

**Q7 Please explain why you said the UKNSCN is '{text of answer from Q6}' to be the UK national focal point for communication with the media and the public?**

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ASK ALL

**Q8 How important is it to you that there is an organisation providing a UK national focal point for interaction between the UK stem cell community and overseas researchers? Please tick one box only.**

- SC *Very important*
- Fairly important*
- Not very important*
- Not at all important*
- Don't know*

[IF Q8=1 OR Q8=2]

**Q9 In your view, how well placed is the UKNSCN to be the UK national focal point for interaction with overseas researchers seeking collaboration? Please tick one box only.**

- SC *Very well placed*
- Fairly well placed*
- Not very well placed*
- Not at all well placed*
- Don't know*



[IF Q9=1 or Q9=2 or Q9=3 or Q9=4]

**Q10 Please explain why you said the UKNSCN is '{text of answer from Q9}' to be the UK national focal point for interaction with overseas researchers?**

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ASK ALL

**Q11 Which of these have you done? Please tick all that apply.**

- MC *Attended the UKNSCN annual meeting in Edinburgh, in April 2008*
- Visited the UKNSCN website*
- Read the UKNSCN newsletter*
- Read the UKNSCN email bulletin*
- Contributed views to the UKNSCN about issues pertinent to public consultations*
- Been present at another UKNSCN event or a presentation given by the coordinator or a member of the steering committee*
- Had contact with the UKNSCN or used a UKNSCN provided service in any other way*
- X *None of these*

[IF Q11=1]

**Q12 You said that you attended the UKNSCN annual meeting in April 2008. How useful did you consider the meeting?**

- SC *Very useful*
- Fairly useful*
- Not very useful*
- Not at all useful*
- Don't know*

[IF Q11=1]

**Q13 How good an opportunity to network with others involved in the stem cell field did the meeting provide?**

- SC *Very good opportunity*
- Fairly good opportunity*
- Not a very good opportunity*
- Not a good opportunity at all*
- Don't know*

[IF Q11=1]

**Q14 Have you discussed collaborative working, or engaged in joint work, as a result of the annual meeting?**

- SC Yes
- No

[IF Q14=1]

**Q15 Please tell us about any discussions or collaborative work that resulted from contacts made at the UKNSCN annual meeting.**

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[IF Q11=1]

**Q16 How likely are you to attend future UKNSCN annual meetings?**

- SC
- Very likely
  - Fairly likely
  - Unlikely
  - Very unlikely
  - Don't know

[IF Q16=1 or Q16=2 or Q16=3 or Q16=4]

**Q17 Why did you say you are '{text of answer from Q16}' to attend future UKNSCN annual meetings?**

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[IF Q11=2]

**Q18 You said that you had visited the UKNSCN website. What did you visit it for? Please tick all that apply.**

- MC
- News about the UKNSCN
  - Information about the UKNSCN events (e.g. the annual meeting)
  - Other information about stem cell science and organisations that operate in the stem cell field
  - Links to UKNSCN publications (e.g. press releases)
  - Links to other publications
  - Links to other organisations
  - Something else
  - Don't know
- X

[IF Q18=7]

**Q19 You said that you had visited the UKNSCN website for 'something else'. Please provide details below.**

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[IF Q11=2]

**Q20 How useful do you find the UKNSCN website?**

- SC
- Very useful
  - Fairly useful
  - Not very useful
  - Not at all useful
  - Don't know

[IF Q20=1 or Q20=2 or Q20=3 or Q20=4]

**Q21 Please could you explain why you find the website '{text of answer from Q20}'?**

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[IF Q11=3 or Q11=4]

**Q22** You said that you have read emails or newsletters from the UKNSCN. How useful do you find these?

- SC      *Very useful*                        
            *Fairly useful*                      
            *Not very useful*                    
            *Not at all useful*                  
            *Don't know*

[IF Q22=1 or Q22=2 or Q22=3 or Q22=4]

**Q23** Please could you explain why you find that the UKNSCN emails or newsletters are '{text of answer from Q22}'?

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[IF Q11=7]

**Q24** You said that you had contacted UKNSCN or used a UKNSCN provided service in some other way that was not listed at a previous question. Please give details of this other contact or involvement below.

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[IF Not Q11=1]

**Q25** How likely are you to attend UKNSCN annual meetings in the future?

- SC      *Very likely*                              
            *Fairly likely*                          
            *Not very likely*                      
            *Not at all likely*                    
            *Don't know*

[IF Q11=8]

**Q26** How likely are you to become involved in any other way with the UKNSCN in future?

- SC      *Very likely*                              
            *Fairly likely*                          
            *Not very likely*                      
            *Not at all likely*                    
            *Don't know*

[IF Q26=1 or Q26=2 or Q26=3 or Q26=4]

**Q27** Why are you '{text of answer from Q26}' to get involved with the UKNSCN in the future?

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ASK ALL

In its corporate plan, the UKNSCN has proposed key areas for development (if you would like to view the UKNSCN corporate plan, click, which will open the relevant page of the UKNSCN website as a new window in your browser).

**Q28** Do you agree or disagree with the following statements? Please tick one box on each row.

SC		Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't Know
	It would be helpful to me if the UKNSCN were to:						
a	Develop the UKNSCN website as a collaborative tool for researchers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b	Maintain a web-based directory of expertise across the sub-disciplines of stem cell science	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c	Continue to develop and expand the UKNSCN annual meeting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d	Further engage with the media to get key messages to the public	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e	Arrange events and other activities to promote interaction between industry and academia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f	Prepare position papers on key issues for policy makers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g	Develop a national strategic plan for UK stem cell science extending to 2015	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h	Work closely with the relevant bodies to ensure appropriate regulation of stem cell science	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i	Provide a patent-watching service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ASK ALL

**Q29** Please indicate the degree to which you agree or disagree with the following statements by ticking one box only for each question.

SC		Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't Know
a	I feel that I am a part of the UK National Stem Cell Network	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b	The UKNSCN represents my views to regulators and policy makers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c	The UKNSCN provides useful resources and events.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d	The UKNSCN represents the UK stem cell community to overseas researchers in a positive way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e	The UKNSCN represents the UK stem cell community to the public and the media in a positive way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f	The UKNSCN is <u>NOT</u> relevant to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



ASK ALL

**Q30 What else should the UKNSCN do to promote stem cell science in the UK?**

**Please describe the role or activity, including your reasons for thinking that the UKNSCN is the appropriate body.**

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**Q31 Is there anything else you would like to say about the future development of the UKNSCN?**

**Please include any views about its management arrangements or sponsorship of its activities.**

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ASK ALL

**The last few questions ask about your role and the type of organisation you work for. This is just to help our analysis of responses to this consultation.**

**Q32 Which of the following best describes your current role? Please tick one box only.**

- SC
- Scientist*
  - Social scientist*
  - Clinician*
  - Communications*
  - Administration/ Management*
  - Financial/Investment*
  - Legal/ IP*
  - Government Policy/ Regulatory*
  - Other*

[IF Q32=9]

**Q33 Please describe your current role.**

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**Q34 Which of the following best describes the type of organisation you work for? Please tick one box only.**

- SC
- Commercial*
  - Academic*
  - Public Sector Research Establishment*
  - NHS/ hospital*
  - Industry body*
  - Learned society*
  - Public sector funder*
  - Charitable funder*
  - Patient group*
  - Government*
  - Other*



[IF Q34=11]

**Q35** Please describe the type of organisation you work for in the box below. Please also include your job title.

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[IF Q34=1]

**Q36** What type of commercial organisation do you work for? Please tick one box only.

- SC *Large pharmaceutical company*
- Bio-technology company*
- Q34=1 *Another type of commercial organisation (write in)* \_\_\_\_\_

[IF Q34=2 OR Q34=3 OR Q34=4 OR Q34=5 OR Q34=11]

**Q37** Do you have any of these commercial interests in addition to your main role? Please tick all that apply.

- MC *Commercial consultancy*
- Spin out company*
- Income from IP/ patents*
- X *None of these*

ASK ALL

**Q38** Which country are you mainly based in? Please tick one box only.

- SC *UK*
- Other EU*
- US*
- Canada*
- Australia*
- New Zealand*
- Russia*
- China*
- Japan*
- South Korea*
- India*
- Brazil*
- Other (please write in)* \_\_\_\_\_

[IF Q38=1]

**Q39** In which country of the UK are you mainly based? Please tick one box only.

- SC *Wales*
- Scotland*
- Northern Ireland*
- England*



ASK ALL

**Q40 Which of the following areas are particularly relevant to you? Please all the categories that apply.**

- MC *Adult stem cells*   
*Embryonic stem cells*   
*Translational medicine*   
*Clinical application*   
*Bio-processing*   
*Law/ Regulation*   
*Social science*   
X *None*   
*Other (please write in)* \_\_\_\_\_

**Q41 Are you male or female?**

- SC *Male*   
*Female*

[IF Q34=1 OR Q34=5 OR Q34=6 OR Q34=7 OR Q34=8 OR Q34=9 OR Q34=10 OR Q34=11]

**Q42 Which of these best describes your current position? Please tick one box only.**

- SC *Head of organisation/ Department*   
*Senior Professional/ Senior Management*   
*Professional/ Management*   
*Executive/ Research*   
*Administrative/ support*   
*Other (please write in)* \_\_\_\_\_

[IF Q34=2 OR Q34=3 OR Q34=4]

**Q43 Which of these best describes your current position? Please tick one box only.**

- SC *Head of organisation/ department*   
*Professor or equivalent*   
*Reader or equivalent*   
*Senior lecturer/researcher or equivalent*   
*Lecturer/researcher or equivalent*   
*Post-doctoral researcher*   
*PhD student*   
*Undergraduate/ Masters student*   
*Other (please write in)* \_\_\_\_\_



ASK ALL

People Science and Policy would like to talk to some people about their views and experiences of the network in more detail.

This would take the form of a short telephone interview, of approximately 20 minutes duration or less.

These interviews will be confidential, and findings will be reported anonymously.

Q44 Would you be willing to take part in a telephone interview as part of this review?

SC	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>

[IF Q44=1]

Thank you for being willing to take part in a short confidential telephone interview.

Please write your name, e-mail address and the telephone number that you would prefer us to contact you with below.

Q45 Name

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Q46 Phone number

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Q47 Email address

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Thank you for taking the time to help the UKNSCN and BBSRC by completing this consultation form. The results of the consultation will help to inform the report of the review of UKNSCN, which will be published in early 2009.

If you want to print a copy of your responses, or review the answers you have given, you should do so now. Otherwise please click on the 'submit' button at the bottom of the screen.

If you have any queries about this consultation please contact Alan Worley at PSP on 020 3102 8137 or email alan.worley@peoplescienceandpolicy.com