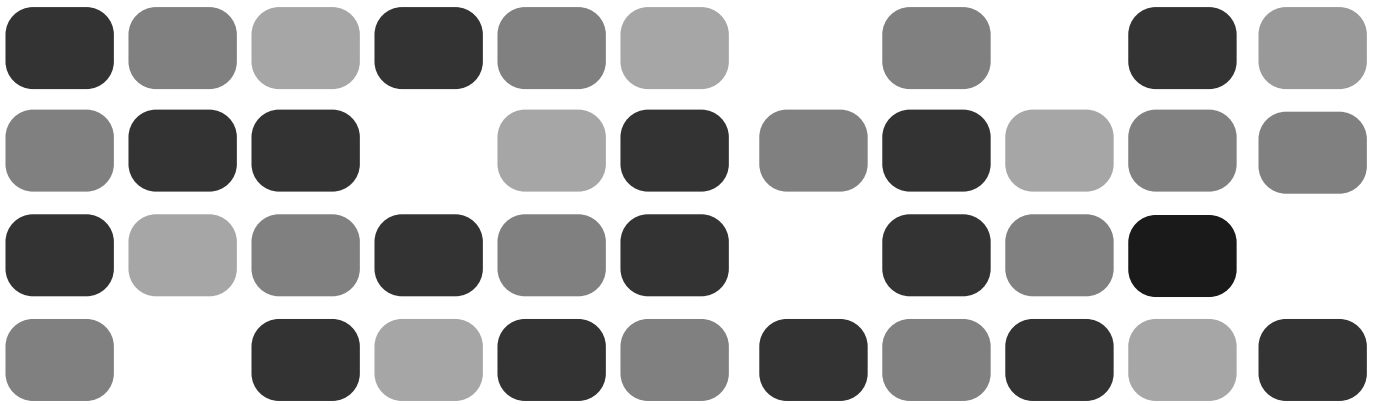


# Review of the Wellcome Trust Biomedical Ethics Programme



Policy Unit  
Published by The Wellcome Trust, London

IC09-2428/1K/09-2001/TH



The Wellcome Trust

## **Acknowledgements**

The Wellcome Trust would like to thank the many people who contributed to this review. We are particularly indebted to all those who gave up their time to complete the questionnaire, attend the discussion symposium and/or participate in an interview.

This review has greatly benefited from the advice and guidance of an Advisory Group that included Margaret Brazier, Alastair Campbell, Imogen Evans and Albert Weale.

	<i>Page</i>
<b>Executive summary</b>	<b>4</b>
<b>1 Introduction</b>	<b>6</b>
1.1 The Biomedical Ethics Programme	6
1.2 Review Aims	7
1.3 Review Method	7
<b>2 Supporting research through the Biomedical Ethics Programme</b>	<b>8</b>
2.1 Knowledge of the Programme	8
2.2 Applications and awards	8
2.3 Application assessment	10
2.4 Project reporting	10
<b>3 Developing the field</b>	<b>11</b>
3.1 Introduction	11
3.2 The Programme scope	11
3.3 Outputs and outcomes of the Programme-funded research	13
3.4 Building capacity	13
3.5 Supporting policy-relevant research	15
<b>4 Communicating the research</b>	<b>17</b>
4.1 Introduction	17
4.2 The audience for Biomedical Ethics Research	17
4.3 How to communicate the research	18
<b>5 Conclusions</b>	<b>21</b>
5.1 Orientation/Position	21
5.2 Funding mechanisms	22
5.3 Administration	22

## Executive summary

1. The Biomedical Ethics Programme was set up as a five-year, fixed-term initiative at the Wellcome Trust in 1997, with a budget of £5 million. The broad aim of the Programme is to support research into the ethical, legal, social and public policy aspects of developments in biomedical science, with a focus on two areas: neuroscience (including mental health) and genetics.
2. This report describes a review (combining a questionnaire survey, interviews and discussion symposium) of the Biomedical Ethics Programme to assess progress towards the three operational objectives of the Programme (listed below) and to inform decisions on the future of the initiative.

The specific operational objectives of the Programme are to:

- i. support timely, high-quality research into the social, ethical and public policy consequences of scientific advances in biomedicine
  - ii. build and enhance national capacity in the field
  - iii. ensure, as far as possible, that research is relevant to public policy and effectively communicated to policy makers.
3. Since its inception to January 2001, 111 full grant applications have been received by the Programme. Some 50 funding awards have been made, to a total funding commitment of just under £3 million.
  4. The Programme has been successful in attracting researchers from a wide range of disciplinary backgrounds, many of these working in disciplinary areas not traditionally funded by the Trust.
  5. While it is too early to assess the tangible research outcomes in any depth, the majority of survey respondents thought that the Programme was achieving a degree of success across all its aims. Over half of respondents (59%) thought that the Programme was supporting research which will inform future public policy considerations; 54% thought that the Programme was enhancing the research in the field; and 51% thought that the Programme was successful in attracting new researchers to the field.
  6. The Programme was thought to be a major force in facilitating the growth of social, ethics and public policy research in biomedical science. The current portfolio of schemes and opportunities available through the Programme were thought to be appropriate capacity- building mechanisms, although it was suggested that greater consideration be given to more long-term commitment and opportunities for funding at all career levels.
  7. Although such objectives might be met by adopting a ‘centres’ approach to funding, it was agreed that this would be premature. It was thought that the creation of physical centres might inhibit the development of the broad range of research needed in this area. Researchers called for the Programme to support the creation of a more ‘virtual’ network, where researchers could meet to exchange ideas and gain knowledge.
  8. The Summer Schools and Workshops funded through the Programme were thought to be particularly useful for fostering collaborations and facilitating multidisciplinary working. It was also suggested that consideration be given to the possibility of supporting both research and meetings of a more international nature.
  9. While the Programme is becoming well known, there is evidence that greater clarity of both the Programme’s objectives and scope is required. This review found concern that the Programme’s current emphasis on genetics and neuroscience, public policy relevance and empirical research possibly narrows the research agenda and may stifle the development of the field.

10. In general both survey respondents and the symposium delegates thought that the Programme is funding research with wide-reaching relevance. Over three-quarters of survey respondents (77%) thought that research funded through the Programme was useful to public policy makers, with a further 73% thinking the research useful to various 'publics'.
11. There was, however, recognition by both stakeholders and researchers that academics are often unaware of the information needs of policy makers. There is little tradition of policy makers using such evidence for policy making in this area and while some researchers have long experience of doing research that speaks to public policy concerns or healthcare practices, many others do not. Symposium delegates welcomed support to help them understand the needs of policy makers and their advisers.
12. In addition, while it was considered important for researchers to be doing work with public policy relevance, some felt that room was required for exploratory research that might not be considered 'relevant' to current public policy agendas.
13. An area requiring further development is in encouraging active engagement between the research community and public policy makers. Around one-third of survey respondents (36%) had already communicated their research outside academia and a further 55% had plans to do so. However, while most researchers planned to communicate their research to all those directly involved, there was limited evidence of communication beyond this arena.
14. The effective communication and dissemination of research to both research participants and those in public policy is pivotal to the success of the Programme, and goes some way to fulfilling the Trust's public engagement corporate objective. To further facilitate this, mechanisms are required (for example, dissemination strategies) to ensure that research is both available and useful to potential users of that research.

# 1 Introduction

## 1.1 The Biomedical Ethics Programme

1. The Biomedical Ethics Programme was set up as a fixed-term, five-year initiative at the Wellcome Trust in 1997, with a budget of £5 million. The broad aim of the Programme is to support empirical research into the ethical, legal, social and public policy aspects of developments in biomedical science, with a focus on two areas: neuroscience (including mental health) and genetics.
2. The specific operational objectives of the Programme are to:
  - support timely, high-quality research into the social, ethical and public policy consequences of scientific advances in biomedicine
  - build and enhance national capacity in the field
  - ensure, as far as possible, that research is relevant to public policy and effectively communicated to policy makers.
3. The Programme has two broad mechanisms to help it achieve its objectives:
  - A funding programme operating in responsive mode (focusing on neuroscience and genetics). All applications are subject to peer review. A panel of experts, drawn from a range of disciplines, makes the decisions on which applications receive support.
  - A programme of capacity-building initiatives to support researchers and public policy considerations and to aid development of national capacity.
4. In addition, the Programme staff support the operation of other departments at the Trust by providing advice on the growing number of internal matters relating to ethics.
5. The funding arm of the Biomedical Ethics Programme offers funding for specific research projects – project grants – and funding designed to enhance capacity in the field by training individuals:
  - Postdoctoral Research Fellowships (three years)
  - Research Leave Fellowships (up to one year)
  - PhD studentships
  - Research expenses (up to £2500), conferences and symposia (up to £2500).
  - Additional capacity-building interventions are also undertaken including annual summer schools and a programme of workshops.
6. Most new and fixed-term/time-limited initiatives at the Trust are reviewed towards their initial endpoint to assess progress. While too early to measure tangible research and career outcomes from the Programme since most awards are in their infancy,<sup>1</sup> it is appropriate to examine the workings of the Programme in practice and anticipate the likely impacts.

---

<sup>1</sup> Many of the traditional measures used to assess research outputs and outcomes from scientific research (e.g. bibliometrics) are not indicative of progress in a field where social research methods are predominantly the tools of choice. The methods employed to evaluate the outputs of the Programme at a later date are likely to differ from those used to attempt to measure scientific achievement.

## 1.2 Review aims

7. The specific aims of this review are to:
- analyse and set in context the funding commitment to date
  - assess the progress of the Programme against its original objectives
  - estimate the impact of the Programme to date
  - assess the current structure of the Programme and identify possible future developments and opportunities for the initiative.

## 1.3 Review method

8. The methodologies employed in this review are as follows:
- Collation and analysis of all applications and awards made by the Biomedical Ethics Programme.
  - Questionnaire survey (277 sent out; 96 returned completed = 35 % response rate<sup>2</sup>). The questionnaire was sent to individuals who had correspondence with the Programme including award holders (see table below for breakdown of responses), rejected applicants, Workshop and Summer School attendees and referees used in the peer review of applications.

Returned questionnaires and relationship to the Programme	
	Response (No.)
<b>Total</b>	<b>96</b>
<b>Project Grant award holder</b>	<b>11</b>
<b>Research Leave Fellowship award holder</b>	<b>2</b>
<b>Research Fellowship award holder</b>	<b>2</b>
<b>PhD award holder</b>	<b>6</b>
<b>Rejected funding applicant</b>	<b>17</b>

There were 99 respondents but only 95 answered some questions

- **Face-to-face interviews** with a sample of potential ‘users’ of the research funded through the Programme (n=5)
  - **Consultation symposium** – held to provide feedback and discussion with a group of researchers who are active in the field (around 40 researchers attended).
9. All extracts taken from interviews are anonymized and coded with a letter, where ‘Q’ indicates a comment taken from a questionnaire ‘I’ indicates a comment taken from an interviewee and ‘S’ a comment from the symposium.

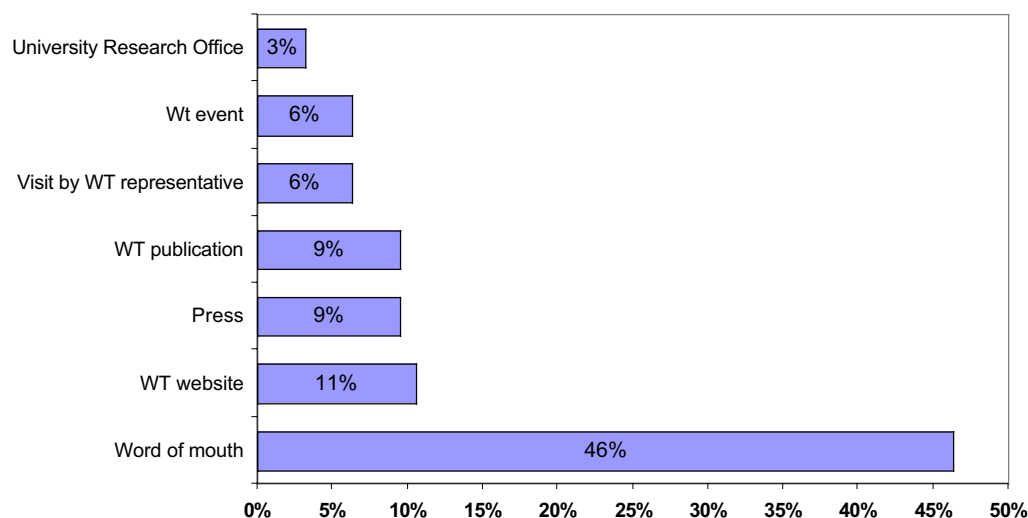
<sup>2</sup> The limited response rate in part reflected the difficulty in contacting a sample of researchers who knew enough about a new Programme in a new (undefined) field.

## 2 Supporting research through the Biomedical Ethics Programme

### 2.1 Knowledge of the Programme

10. Survey respondents were asked how they found out about the Programme. Nearly half (46%) had heard about the Programme through ‘word of mouth’ (Figure 1).

**Figure 1 How respondents found out about the Biomedical Ethics Programme (n=95)**



### 2.2 Applications and awards

11. Since its inception to January 2001, there have been 111 full applications submitted to the Biomedical Ethics Programme (see Table 1). Some 50 awards have been made, to a total funding commitment of £2 930 304 as of January 2001.
12. While the total number of applications is small, the success rates for applications to the different schemes are broadly in line with Trust averages for the biomedical science that it funds.
13. The Programme has attracted researchers from a wide range of disciplinary backgrounds<sup>3</sup> – encompassing the humanities, social sciences, clinical and basic sciences (Table 2). Many of these researchers are new to the Trust, working in disciplinary areas not normally funded by the Trust.

**Table 1: Applications and awards to the Biomedical Ethics Programme**

Funding Scheme	Applications (number)	Awards (number)	Success rate	Amount committed
Project Grants	42	17	40%	£1 764 008
PhD studentships	38	10	26%	£530 787
Post-doctoral Fellowships	8	4	50%	£343 980
Research-leave Fellowships	4	2	50%	£234 539
Symposia	18	16	89%	£55 790
Research Expenses	1	1	100%	£1 200
Total	111	50	45%	£2,930,304

<sup>3</sup> Disciplinary backgrounds are derived from the application forms, using job title as a proxy measure.



<b>Table 2: Disciplinary background of applicants (principal &amp; coapplicants)</b>	
Disciplinary background	Number
Sociology	10
Medical Genetics	9
Ethics (Medical/Other)	9
Medicine	5
Clinical Psychiatry	4
Public Health	3
Political Science	3
External Advisory Body	3
Philosophy	2
Health Services Management	2
Law	2
History	1
Epidemiology	1
Biomedical Science	1
Anthropology	1

14. Applications originated from a wide range of institutions, again some not the Trust's major award winners. Tables 3 and 4 list the top ten institutions ranked in order of the number of applications to the Programme.

<b>Table 3: Project grant applications by institution</b>			
Institution	Applications	Awards	Sum awarded
Imperial College	4	1	£164 446
University of Aberdeen	4	1	£62 243
University of Nottingham	4	1	£117 009
University of Cambridge	3	2	£214 760
University of Oxford	3	1	£38 471
Cardiff University	2	1	£122 300
King's College London	2	2	£173 896
University of Wales College of Medicine	2	1	£163 103
University of Bristol	2	1	£185 853
University of Sheffield	2	0	–

<b>Table 4: Career development applications by institution (PhDs, Fellowships and Research Leave Fellowships)</b>			
Institution	Applications	Awards	Sum awarded
University of Nottingham	9	2	£106 878
King's College London	4	3	£153 671
University of Glasgow	3	0	-
Cambridge University	2	2	£112 248
Cardiff University	2	1	£200 171
Goldsmiths College	2	1	£51 548
University of Aberdeen	2	0	-
University of Bristol	2	1	£49 535
University of Edinburgh	2	0	-
University of Oxford	2	2	£112 490

## 2.3 Application assessment

15. There was some concern about the process of assessing applications, specifically the composition of the grant-awarding Panel. Respondents questioned how well the Panel membership represented the broad range of disciplines encompassed by the Programme.

“It may well be that the panel who are making decisions about funding do not have a sufficient representation of people with an ethics background and hence are not appreciative of the merits of applications that are being put to it.” Q

“I’m not sure about the composition of the Panel and wonder how often this gets reviewed given the expansion of interest and researchers in this field.” Q

## 2.4 Project reporting

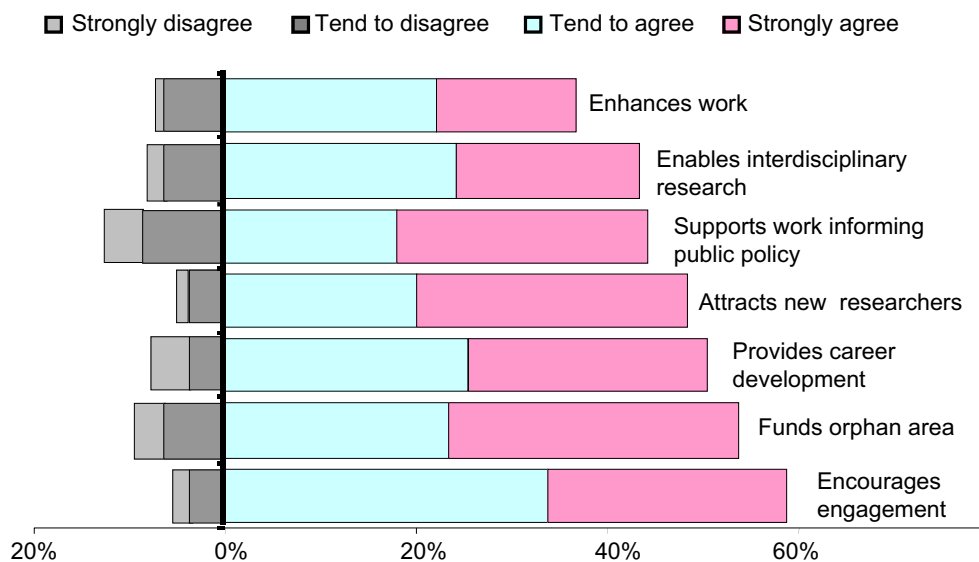
16. Funding bodies have traditionally kept their demands for end-of -PhD/fellowship/project reporting to a minimum, through a desire to reduce the administrative burden on the academic researcher. However, the increasing demand to demonstrate the payback from research and for funding bodies to be more transparent about their activities has led to more proactive management of the outputs of research.
17. The drive for the integration of research findings into policy makes the Biomedical Ethics Programme an ideal testing ground to explore more innovative ways of project reporting. One such area, suggested both in the survey and at the symposium, was the production of both lay/public and policy summaries from all funded work.
18. The terms and conditions agreed on receipt of Trust funding could be used to encourage researchers to consider the dissemination and accessibility of their research findings beyond the academic arena. Methods of dissemination are discussed more fully in Part 4.

### 3 Developing the field

#### 3.1 Introduction

19. As described, the three broad operational aims of the Programme are to:
- support timely, high-quality research into the social, ethical and public policy consequences of scientific advances in biomedicine
  - build and enhance national capacity in the field
  - ensure that research is relevant to public policy and effectively communicated to policy makers.
20. In the survey researchers were asked how far they thought the Programme was meeting its main aims (Figure 2). The majority agreed or strongly agreed that the Programme was meeting aspects of its aims, particularly supporting work which was thought to inform public policy (59%).
21. However, the Programme was thought to be achieving less success in ‘encouraging engagement between the research community and policy makers’, with only 37% feeling that the Programme was achieving this.

**Figure 2. Achieving the Programme’s aims**



Base: Number of respondents=95. Figure excludes those not expressing an opinion.

#### 3.2 The Programme scope

22. The funding arm of the Biomedical Ethics Programme has to date operated broadly in responsive mode, while encouraging applications with a focus on genetics and neuroscience. This emphasis on ‘genetics and neuroscience’ has generated confusion about the overall aim and operational identity of the Programme.
23. There was a perception that the focus on genetics and neuroscience was to the exclusion of other areas.
- “Too narrow focus on genetics and neurosciences – you say this to prevent overlap but bioethicists can’t really apply for other medical programmes.” Q
24. There was also a feeling that associating the initiative with genetics and neuroscience ran counter to the capacity-building aim of the Programme, creating artificial ‘specialisms’ in a newly developing field.

“.. what is funded is first rate. But the strict limits on what is ‘priority’ for the Programme are – I find – very restrictive... interesting ethics and public policy work which is not to do with high science (genetics, neuroscience) has no chance of being funded, but who else will fund it responsibly in the UK?” Q

25. A second area of contention was that the emphasis on funding empirical work imposed further restrictions for researchers. This again was thought to inhibit the development of the field:

“Wellcome is not so far as I am aware supporting Bioethics or biomedical ethics. It is supporting empirical work relating to bioethics.” Q

“I am a bit worried by the very strong preference for bioethics with an empirical research dimension. I am doing a project which has such a dimension, and have been greatly stimulated by having to engage with empirical research. But some very valuable work in bioethics is not empirical at all, and it seems a pity if it is excluded from support.” Q

26. The general consensus from the research community was that the remit of the Programme should be broad-based and should, in fact, be widened further, with international research and clinical bioethics highlighted in particular as possible future areas for funding.

“Broaden the range of topics covered both vertically and horizontally – include research on clinical implications on processes of decision making about ethical issues.” Q

“Currently leaves out international bioethics.” Q

27. As discussed in Part 3.5, it was also thought that it may be better for the development of the field if the Programme reduced its emphasis on policy relevance, particularly given the difficulty in identifying what might be policy-relevant in the future.

“Danger of restricting the range of research problems – need to take a broad and long range view of potential policy issues.” Q

“The Programme is too keen on ... ‘impact’. Relevance, yes, but there is no way to judge the impact of most work on bioethics.” Q “Tendency, in a climate of tight public spending, to assume that research is somehow ‘pink and fluffy’ and not quite relevant to the day to day cut and thrust.” Q

“Tendency, in a climate of tight public spending, to assume that research is somehow ‘pink and fluffy’ and not quite relevant to the day to day cut and thrust.” Q

28. Furthermore, it was felt that commissioned research may be better able to meet policy makers’ needs than responsive funding.

“Waiting for the research community to spontaneously produce policy relevant answers could take some time if the ‘responsive’ model alone is used.” Q

29. This review therefore found the need for greater clarity and statement of the aims of the Programme, so that the research community and research users are clear whether the Programme supports empirical research on:

- the social and ethical implications of biomedical research per se
- the social and ethical implications of biomedical research funded by the Trust (hence the focus on genetics and neuroscience)
- issues raised in the policy arenas, following public consultation.

### 3.3 Outputs and outcomes of the Programme funded research

30. To date there have been around 15 journal papers (published or in press) and several contributions to book chapters based on research that has been funded through the Programme. Several of the research projects funded have been high profile and have generated media interest.
31. It is, however, too early to determine the full extent of the tangible publication and career outcomes of the research funded through the Programme. It is therefore important to ensure that the current funding mechanisms are appropriate to support the conduct of ‘timely, high-quality research’ that will have these tangible research and career outputs and outcomes in the future.
32. The current portfolio of schemes and opportunities available through the Programme was generally thought to be appropriate. It was felt that a good balance was struck between offering funds for specific research projects (project grants), funds for career development (PhD, Fellowships) and funds for various support activities (Summer Schools).
33. There was, however, some concern about the lack of long-term commitment to the area, particularly from individuals who had moved into the field from another discipline. To reduce this potential insecurity, respondents suggested the development of initiatives to support career development (for example, funds to provide writing breaks).

### 3.4 Building capacity

34. Biomedical ethics is not a clearly defined ‘discipline’ with discrete boundaries; it is inherently multidisciplinary. Indeed many researchers described the necessity for this approach to address biomedical ethics issues:

“By its nature biomedical ethics research involves cross-discipline studies. It is an advantage to have relevant experience in cross-discipline research.” Q

35. The role of the Biomedical Ethics Programme in encouraging multidisciplinary research was widely welcomed. By working with new ‘partners’ researchers were able to approach issues in novel and exciting ways.

“As a frustrated social scientist I have had a real opportunity to get involved in empirical research whilst supported and mentored by much more experienced researchers. In return I have helped them to look into profoundly ethical issues which might otherwise have been overlooked.” Q

36. More practically, many respondents described a difficulty in obtaining funds for research of an inherently multidisciplinary nature.

“It is difficult to get funding as a postgraduate for inter-disciplinary research but the Programme’s willingness to fund such research enables valuable work to be produced which would otherwise probably not take place.” Q

“I would have had difficulty having this research funded since it is difficult for a lawyer to get funding to study anything outside the traditional focus of the law.” Q

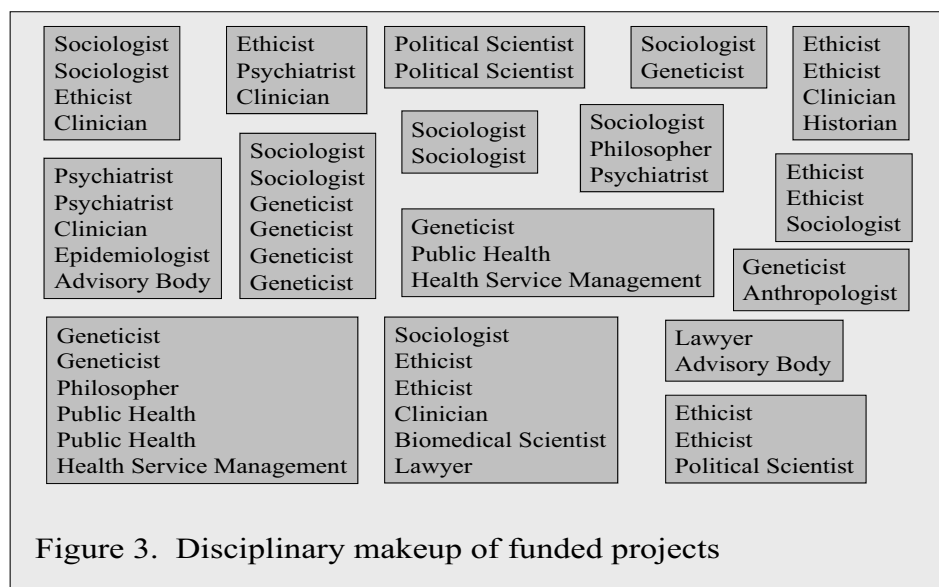
37. There was concern that it is often difficult to encourage researchers to get involved in multidisciplinary research that might have less value in, for example, the Research Assessment Exercise (RAE); the ‘cost’ of transfer to the field may be too great to attract high-calibre researchers to apply to the Programme.

“I am not sure that the Programme has done a good job in attracting really first class people.” Q

38. There was evidence that it was difficult to attract people into the field. It was suggested that some kind of conversion support was required.

“We are finding it hard to get people in at the bottom, because the retraining opportunity costs to established clinicians or mid-training professionals are high.” Q

39. All the project grants funded involved more than one researcher and they almost always involved a multidisciplinary team. Figure 3 illustrates the composition of the research teams for the project grants funded by the Programme (one box = one project). The Programme hoped to attract individuals from disciplines outside the field of bioethics to begin work in the field and this seems to have been successful at both junior and senior levels.



40. The Programme does not currently provide support for programme grants or centres. And the need for creating some sort of ‘critical mass’ of researchers doing biomedical ethics research loomed large in many respondents’ thoughts.

“I would be keen to submit a programme grant to access some core funding to develop a ‘critical mass’ of interested researchers.” Q

41. There were a number of calls for the creation of centres. However, discussion at the symposium generated a consensus that concentration/co-location of bioethics researchers would be premature. It was felt that the creation of physical centres would not be conducive to generating the breadth of research needed.
42. Since the Programme does actually receive requests for funding through the ‘programme grant’ and ‘centres’ approach, although it may be premature to fund research through these mechanisms at the moment, it is important to maintain flexibility and perhaps review this policy at regular stages.
43. Many researchers called for the support of a more ‘virtual’ network, rather than centres, where they could meet on a regular basis to exchange ideas and gain knowledge of others working in the field.

“Conferences are a rather traditional format and frequently serve only as a forum for self-publicity! Perhaps a bulletin either printed or electronic could act as the source for early pre-researched discussion.” Q

“1) Newsletter/advertise more on the website 2) Host online discussion/interest groups 3) More invited seminars along previous lines.” Q

44. The Summer Schools and Workshops were thought to be useful mechanisms for fostering collaboration, as well as dissemination. It was suggested that these should extend beyond the UK.

“The Summer School... brought together individuals from different fields and engendered stimulating ideas.”

“As a result of a workshop, I am now collaborating with a medical ethicist and a gynaecologist who work in another university.” Q

“There is a space to support meetings of a more international nature, perhaps looking for partnerships in Europe and the USA.” Q

45. To this end the Trust may want to consider enhancing the Summer School and Workshop Programmes, creating more structured seminars and developing additional mechanisms to facilitate multidisciplinary working.

### 3.5 Supporting policy-relevant research

46. In general both the survey respondents and the symposium delegates thought that the Programme is funding work with wide-reaching relevance in a variety of settings and contexts.

“The research has good practical and public policy edge. I would like to see this given a higher explicit profile, rather than merely being about ethics, which I think is how the Programme is often perceived by outsiders.” Q

47. While too early for many of the research findings funded through the initiative to have influenced public policy directly, the indications were promising.

“The Programme is generating good research which will in time filter into the decision making process.” Q

“The work supported could and should help inform public policy. Whether it does or not depends upon dissemination of results and their uptake by policy makers.” Q

48. Around half (48%) of survey respondents considered themselves to be involved in public policy making, at a variety of levels, ranging from government advisory bodies (such as the Human Genetics Commission), to local ethics committees and patient groups.

49. There is, of course, a difference between the *perceived* usefulness of a piece of research and its *actual* use. Research stakeholders felt that academics were often unaware of the information needs of policy makers.

“Unfortunately, researchers don’t know how policy is formulated because the framework is not transparent and so don’t know what role to play.” I

50. In addition, it was felt that the timescale required for the production of the research produced in academia often does not concur with a policy maker’s information requirements.

“Policy makers need good quality evidence... but they use much quicker, dirtier pieces of research.” I

“There may be tensions between academic research and research for policy development – in terms of time and resources required. Government departments tend to fund quick pieces of work to directly address policy questions – at huge costs. Academic work may be slower and require less resources if individuals are responsible for the entire project.” Q

51. Finally, there was a feeling among researchers that it was often difficult to define ‘policy relevance’ and to anticipate what may have policyrelevance in the future.

52. Furthermore, while the concept of policy-relevant research was generally embraced, there was concern that the needs of policy makers should not drive the research agenda.

“This is a strong element of the Programme – sometimes I think it would be nice to have a little more space for more theoretical work but I think the policy and empirical thrust is necessary at this stage to emphasise the difference from funding for normative bioethics.” Q

“Work should not all be policy driven... need to question whose policy is it and why it exists too – the role of the social scientist.” Q



## 4 Communicating the research

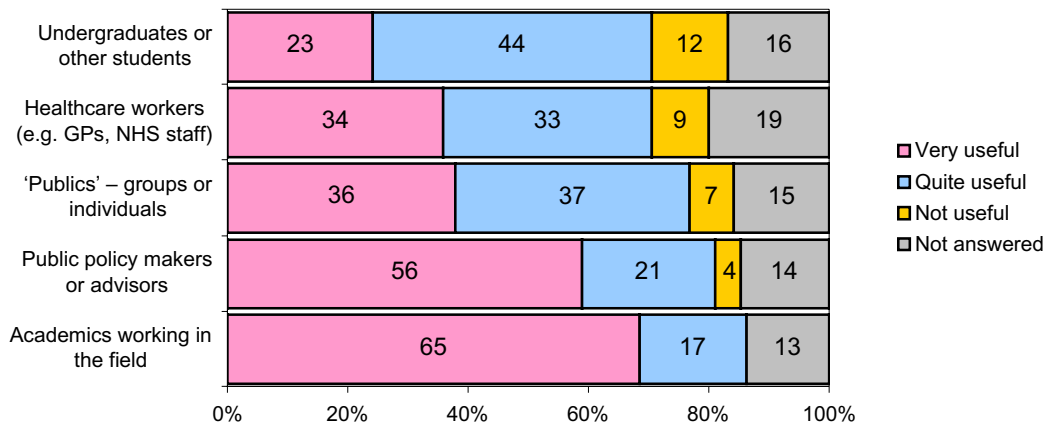
### 4.1 Introduction

53. An important operational objective of the Biomedical Ethics Programme is to ensure that relevant research is effectively communicated to policy makers – implicitly that the research should have *impact* in the wider arena. This section explores how far the Programme has been able to do this, to date, and the issues involved.

### 4.2 The audience for Biomedical Ethics research

54. Respondents were asked to identify which audiences could potentially find their research useful. As Figure 4 shows, the research funded by the Biomedical Ethics Programme was thought to be useful to a wide-ranging audience, although academic audiences were thought the most likely end ‘users’.

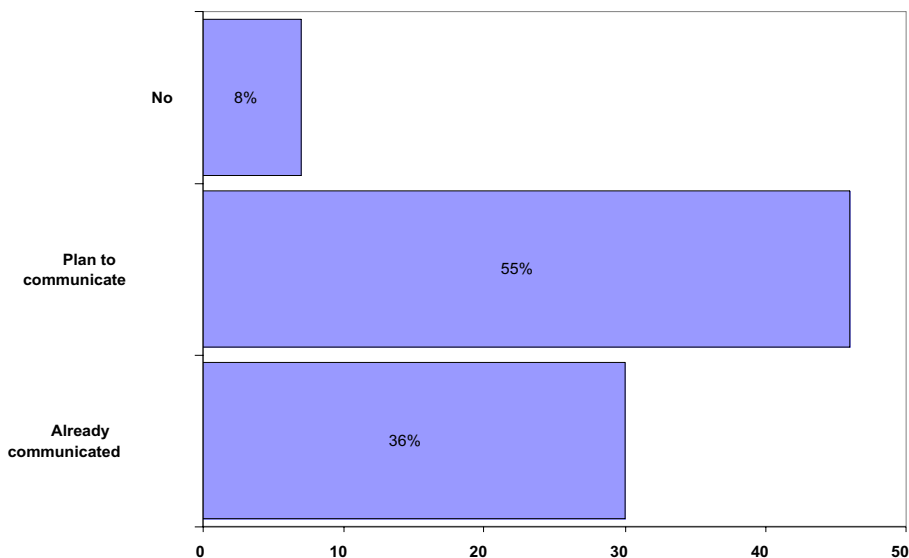
**Figure 4: How useful is the Programme’s research to different audiences.**



Base: Number of respondents=95. Figure excludes those not expressing an opinion

55. Researchers were asked about plans to communicate their research findings beyond the academic arena. Over a third of respondents (36%) had already communicated their research outside academia; a further 55% were planning to (Figure 5).

**Figure 5. Have you communicated findings outside academia? (n=83)**



56. A minority 8% of respondents had no plans to communicate their research outside academia. It may be that they had no messages to convey, or felt that this was not part of their role as an academic researcher.
57. Several researchers could identify a specific audience group for their research and in several cases potential research users and stakeholders were actively involved in the research. Box 1 provides examples of current ‘user’ involvement in research in the field. However, while most researchers did have an idea to whom their own research would be of use, this was often not made explicit in their application.
58. Again there was concern that the requirement to involve users/stakeholders in the research process, while a worthy ideal, should not affect the independence of the research, and the right of the researcher to reach their own conclusions.

“I think that the funding of dissemination seminars should be permitted within projects. Also a meeting of Programme directors outlining the implications of their work for users, policy and proactive. ... the aim should not be harmony and consensus, which so often stifles debate, but rather an open and honest dialogue about what these different actors can learn from each other.” Q

59. In addition to identifying the potential audience and stakeholders for a particular piece of research, thought needs to be given to how the key messages will be conveyed.

#### **BOX 1 – Comments on involvement of ‘user’ groups in research**

“Early discussions have taken place with patient groups about the work underway. They have found this interesting and challenging.”

“My immediate target will be the practising genetic counsellors and also graduate students.”

“We’ve recruited public policy makers and professional body members onto an Advisory Group, which should improve our chances of fruitful dissemination.”

“Communicated to several research ethics committees (including lay persons) and at seminars which include non-academics. I hope this gives a wider understanding of the complexities of international health research.”

“I am consulting with Mind, Sane, and the Zito Trust.”

### **4.3 How to communicate the research**

60. Effective communication of research findings is a key operational objective of the Programme. There are three basic levels (models) of communication of the research the Programme funds and there was mixed opinion on which of these was most appropriate:

**Model 1** – dissemination/communication is the responsibility of the academic researcher

**Model 2** – the Programme should provide support to facilitate the researcher to carry out communication/dissemination activity

**Model 3** – the Programme should conduct its own programme of communication/dissemination.

61. Most respondents embraced the need for communicating and discussing their research in the wider environment; not just through academic publication (Model 1).
62. Researchers acknowledged the need to tailor findings to particular audiences and it was interesting to note the different methods by which researchers planned to inform and engage their audience in their research (see Box 1). There was evidence of dissemination strategies already in place (also see Box 1) and, as Box 2 illustrates, these strategies involved a wide range of agencies.

<b>BOX 2 – Current research dissemination strategies</b>	
Involvement of:	<ul style="list-style-type: none"> <li>• Advisory groups</li> <li>• Consumer groups</li> <li>• Ethics committees</li> <li>• Government advisory committees</li> <li>• Parliamentary Office of Science and Technology (POST)</li> <li>• Patient groups</li> <li>• Trade unions</li> </ul>
Open meetings	
Science festivals	
Citizens' juries	
Research charities	
Academic conferences	
The media – national and local press	
Grey literature	
Newsletters	
Website – with guidelines	

63. Many felt that the Programme could support researchers to conduct dissemination activities (Model 2). In the survey researchers were asked how the Programme could support this. A common suggestion was the hosting of workshops involving participants from a range of backgrounds:

“By organising conferences or symposia addressed to particular practitioner or user communities, or maybe by stimulating programme makers in the mass media to address these issues in a documentary.” Q

64. In addition, if the Programme aims to support research with relevance to public policy then it should request that researchers submit proposals that clearly describe the context and (potential) relevance of their research. Many respondents also thought that researchers should be encouraged to produce more accessible versions of their research and that the Trust should be more proactive in helping researchers develop communication strategies:

“I would like to see academic institutions encouraged to accept a more accessible style of academic work that would allow for more interesting and engaging theses to be produced, and a wider readership.” Q

“When I was funded by the Joseph Rowntree Foundation I was required... to compose a brief and punchy statement of findings. The ‘Findings’ took the form of a glossy pamphlet and was distributed to policy makers etc outside of academia.” Q

65. Finally, several researchers felt that the Trust should itself assume an advocacy role and actively communicate the findings of the research it funds (Model 3). However, this would also potentially compromise the independence of the researcher and may eventually result in the Programme only being willing to fund issues that were not in any way difficult or contentious for the Trust. In this way the development of the field would be stifled.
66. Finally, there was also evidence that the research community was not as informed as they could be about the nature of the research the Programme is funding. This indicates the need for further marketing activity.

“The research funded by the Trust stays within pretty traditional disciplinary lines. Although discussion across disciplines is encouraged by summer schools... I am not aware of any interdisciplinary research resulting from Trust funding.” Q

## 5 Conclusions

67. This review found the Biomedical Ethics Programme to be a widely welcomed, unique resource.

“There is a niche that Wellcome has filled in funding research which focuses specifically on biomedical ethics.” Q

“The Trust is one of the only funding agencies supporting bioethics in Great Britain.” Q

68. It is too early to assess the tangible research outcomes in any depth, but there is good evidence to suggest that the Biomedical Ethics Programme has facilitated the development of the field. Specifically, the Programme was thought to have:

- provided a unique funding source in an area of growing importance
- provided funding to address difficult contemporary ‘ethics and society’ issues
- nurtured and supported growth in this area
- funded research perceived to be relevant to the public and policy makers
- fulfilled some of the Trust’s corporate objectives.

69. There are three broad areas where change may enhance the impact of a Trust biomedical ethics initiative:

- Orientation/position of the Programme: What is the Programme trying to achieve?
- Funding mechanisms: What activities will best assist the Programme to achieve its aims?
- Administration: How should these activities be supported?

### 5.1 Orientation/Position

70. Key to the future of the Programme was the need for greater clarity of both the Programme’s objectives and scope. While the Programme is becoming well known, there is misperception of its priorities. Some respondents thought the Programme concentrated too much on ethics; some thought it was too empirical; others thought that there was not enough priority given to ethics.

71. This review found concern that the current emphasis on policy-relevant and empirical research may stifle the development of the field. It is, however, important that the focus of the Programme is in line with the requirements of the Trust in funding this type of research.

72. The importance of policy relevance and translation of research findings into practice, as part of the Trust’s overarching aims, should be emphasized. In addition, the information needs of various research ‘users’ should be considered by all successful applicants to the Programme.

## 5.2 Funding mechanisms

73. The current range of schemes and opportunities available through the Programme were generally thought to be appropriate although there was some concern about the lack of long-term commitment and opportunities for funding at all career levels
74. However, although the survey contained calls for the creation of centres, consensus at the symposium was that concentration/co-location of biomedical ethics researchers, at this stage, would be premature. Instead there should be support of 'virtual' centres, to facilitate the regular meeting and networking of researchers in the field.
75. There was consensus that structured seminars, workshops and summer schools are fruitful capacity building interventions as well as useful for dissemination, particularly so when bringing together researchers from the social and the biomedical sciences and facilitating multidisciplinary working. Consideration should also be given to the possibility of supporting meetings of a more international nature.

## 5.3 Administration

76. This review found universal praise for the Programme staff. However, there were many suggestions for changes to the way the Programme is administered.
77. There were concerns about the basic grant application form, with many researchers feeling that the 'hard science'-driven questions made the application procedure arduous and off-putting. To enable it to select and fund the best-quality research, the Trust must ensure that it gets the best-quality information from applicants by asking the most appropriate questions.
78. The composition of the grant-awarding Panel should be broad ranging and the recruitment procedure transparent. It may be timely to consider which other sectors would be usefully represented on the assessment panel (for example, ethics committee representatives, GPs, industry, policy makers).
79. Finally, the effective communication and dissemination of the research funded is vital to ensure the future success of the Programme. Consideration should therefore be given to how best to facilitate the communication of research findings beyond the academic arena. This includes activities to develop ways of making research useful.