



Nuffield Council on Bioethics Evaluation

Prepared by:	Firetail Ltd: Andy Martin, Helen Tweed, Ruthann Hughes and Ilse van der Hoeven
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1 Executive summary

The Nuffield Council on Bioethics was founded in 1991. It is an independent body that examines and reports on ethical issues in biology and medicine. Its terms of reference require it:

- To identify and define ethical questions raised by recent advances in biological and medical research in order to respond to, and to anticipate, public concern;
- To make arrangements for examining and reporting on such questions with a view to promoting public understanding and discussion; this may lead, where needed, to the formulation of new guidelines by the appropriate regulatory or other body;
- In the light of the outcome of its work, to publish reports; and to make representations, as the Council may judge appropriate.

As it comes to the end of its 2012-2016 funding cycle, this report seeks to evaluate its impact over that period, consider its progress against its strategic objectives and frame questions for its future strategy.

Perceptions: The Nuffield Council on Bioethics is a highly regarded and reputable body playing an important role in the UK's policy landscape

All stakeholders interviewed for this evaluation believe that the Nuffield Council on Bioethics has a high level of credibility. This is the result of its academically rigorous report writing process, its people and the quality of the reports. The Nuffield Council on Bioethics' outputs are widely and almost unanimously understood to be of high quality. To many, the Nuffield Council on Bioethics is the "household name" in bioethics.

Role: The Council's traditional role is to convene representative groups in order to inform policymakers. Many stakeholders consider the Council's role should be conceived of more widely, and the Council should engage with a broader set of audiences

Among the stakeholders interviewed, there is no single accepted definition of bioethics or the bioethics sector. As a result, views on the role of the Council differed, largely based on the individual's definition of the bioethics landscape. Stakeholders interviewed could be broadly categorised into two groups. For the first, the bioethics sector primarily consists of academics and policy makers. Stakeholders in this group are largely in favour of the original role of the Council: to inform policymaking with balanced academic views on bioethics. The second group views the sector more broadly and also considers bio-medical industries, professional groups, practitioners and civil society groups to play an important role. Many members of this group call for a more inclusive approach.

Impact: The Council can point to significant direct impact with UK policymakers on specific issues. It has also had a demonstrable, though more indirect impact on academic researchers, funders, the public, international and the private sector

Stakeholders described the impact the Nuffield Council on Bioethics has had on a variety of audiences. Many referred to direct policy impacts. The report on '*Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review*' is believed to have had a direct and significant impact on the government's decision to allow mitochondrial replacement. A media stakeholder commented that it would be difficult to identify a debate about mitochondria replacement where the Nuffield Council on Bioethics was not mentioned. The

Council's impact on academic bioethics is reported to be significant by all academic stakeholders interviewed during this process. Other stakeholders including those from the private sector, NGOs and practitioners reported that they take the work of the Nuffield Council on Bioethics seriously. It is difficult to measure the impact of the reports on the general public, but the Council has frequent engagement with the media.

Operating model: The Council's 'core process' for selecting, writing and disseminating reports is one of its great strengths, but also the source of some of its weaknesses

The Nuffield Council on Bioethics has a 'product' focussed operating model, designed to produce its reports. For some stakeholders interviewed, the process itself was the most important output of the Council – "an enterprise in public rationality" - and the basis of the organisation's mandate and authority. However, the current process is reported as inflexible, slow and 'one-size-fits-all'. Some stakeholders felt that the gaps between launches, working groups and publications were too long and that some issues demanded quicker responses than the Council was able to give. The importance of the process is such that the Council is guided more by its processes and procedures than its strategic objectives.

Topic selection: The Council is generally thought to have picked the right topics to work on. Issue selection is expected to become more difficult in the future

Most stakeholders felt that the topic process is robust and that few topics have been 'missed' by the Council. Several had participated in forward look meetings, and felt that the calibre of the people involved gave them confidence that the 'right' topics were under consideration. However, the Council has not been able to address all topics within the timescale that many stakeholders would like. Picking topics in the future could become more difficult as the world of bioethics becomes more complex and as the boundaries between ethics, the biological sciences, politics and technology blur.

Strategy: The Council has made mixed progress against the strategic objectives described in its 2012-2016 strategy document. Many of the Council's achievements go beyond the priorities outlined in that document and the objectives described in that document do not appear to have been the major driver of change for the organisation.

In 2011/2012, the Nuffield Council on Bioethics developed a new strategy. The organisation has made some progress against the strategic objectives set out in that document. Many initiatives, such as the creation of an affiliates database and more Council subgroups have been completed. However, the day-to-day salience of the strategy appears to have been low. The most significant challenges and questions of strategy – the topics to work on, the nature and composition of the working groups, the audiences to be engaged - are considered in reference to the core report development process. Success in these areas is outside the scope of the 'strategy' as it was described in that document. Most stakeholders engaged during this evaluation had little awareness or understanding of the strategy or the objectives, especially when compared to their understanding of the report-writing process and the most pressing strategic questions faced by the Council.

Landscape: Bioethics is becoming more important and more complex. The Council plays a unique role in the sector.

The majority of interviewees think that bioethics is now more important than ever. There are a growing number of organisations with an interest in bioethics and the landscape is becoming more crowded. Nevertheless, the Nuffield Council on Bioethics is unique. For most

stakeholders interviewed the Council does not have direct competitors or peers in the UK. Many refer to the work of the Royal Societies, Royal Academies and think tanks that occasionally covers similar topics to the Nuffield Council on Bioethics. For most, however, this overlap is limited. Stakeholders do not regard the Council's international peers as competitors, as these bodies do not write for a UK audience.

Future direction: There is a clear consensus that the Nuffield Council on Bioethics should be maintained. It should consider questions of future strategy whilst ensuring that its reputation for quality is maintained

There is currently no consensus on the future direction of the Council. A more proactive strategy is needed to consider and manage change, based on a clear understanding of how the world is changing and the Council's emerging role in that world. In this next funding period, the Council should set a strategy that addresses questions around the following areas:

- Audiences and communications
- Operating model
- International role
- Funding model

These questions arise largely in response to issues raised by stakeholders critiquing the current approach, identifying opportunities for increased impact and anticipating areas of increased demand.

2 Background, objectives and approach

2.1 Background and objectives

The Nuffield Council on Bioethics examines and reports on ethical issues raised by new advances in biological and medical research. Its mission is to promote and support public discussion and inform policy through identifying and exploring ethical issues that arise in bioscience.

The Council has been funded by the Nuffield Foundation, the Wellcome Trust and the Medical Research Council since the early 1990s through a succession of five-year grants. It is not a separately constituted legal entity, but operates as part of the Nuffield Foundation. As the Council is approaching the end of its current funding period (2012-2016), it is preparing its strategic plan and future funding proposal for 2017-2021. This presents an important opportunity for the Council to reflect on progress to date and respond to important changes in its landscape as it sets priorities for the next 5 years.

The Council takes a consultative and evidence based approach to strategy development. It is conducting an internal review on its impact and performance. Alongside this activity it appointed Firetail to conduct an external review. Specific objectives of the this review were to:

- **Understand the Council's external environment:** To increase understanding of the landscape the Council works in and how it is changing. To understand how stakeholders and the sector view the Council, in terms of its vision and approach, the effectiveness of its ways of working and impact it makes
- **Evaluate achievements:** Consider progress towards the Council's strategic objectives and its overall vision, taking into account the views of relevant stakeholders. Highlight key successes and failures, understand and explain the reasons behind these, and identify areas for improvement
- **Anticipate change:** Identify key themes, opportunities and threats affecting its model of change and place in the bioethics landscape
- **Frame strategy:** On the basis of all of the above, generate clear recommendations for the Council's next strategic plan.

2.2 Approach

The review of the Nuffield Council on Bioethics comprised a series of activities to evaluate the Council's achievements to date and to inform its future strategy, namely through:

- A review of the Council's documentation
- A series of 23 qualitative interviews with key stakeholders
- A quantitative stakeholder survey (shared online with wider stakeholder groups)

Review of the Council's documentation

Firetail reviewed the Council's existing documentation and data to develop a clear picture of its workings. This included reports, publications, financial information, media monitoring documents, funder applications and strategic plans. Reviewing these documents has informed our understanding of the Council's objectives and ways of working and enabled us to assess its recent achievements and performance.

Stakeholder interviews

Between April 21st and May 11th Firetail conducted 23 evaluation interviews with a sample of the Nuffield Council on Bioethics' key stakeholders. The sample (outlined below) was generated from a source list of stakeholders provided by the Nuffield Council on Bioethics. Interviews were conducted with stakeholders from a broad range of roles and organisations including all stakeholders identified as "essential" on the source list:

- Policy makers and politicians (3 interviews)
- NGO and civil society (3 interviews)
- Industry (2 interviews)
- Academia (3 interviews)
- Regulatory bodies and professional societies (3 interviews)
- Research Councils (1)
- Media (2 interviews)
- International peer organisations (2 interviews)
- International governmental organisations (2 interviews)
- Nuffield Council on Bioethics Members (2 interviews)

The stakeholders were predominantly located in the UK. We conducted 4 interviews with stakeholders based in Europe or in the US.

The discussions were conducted over the telephone (with the exception of the interview with one stakeholder from the Council, which was conducted in person). Questions were based around a semi-structured discussion guide, which is appended to this document. The conversations took place on a non-attributable basis. Recordings of the interviews have been analysed in the preparation of this report.

Quantitative component

Between the 1st and 15th of May Firetail ran an online survey (hosted on SurveyMonkey). A total of 99 respondents completed the survey. The Nuffield Council on Bioethics promoted the survey in a number of different ways:

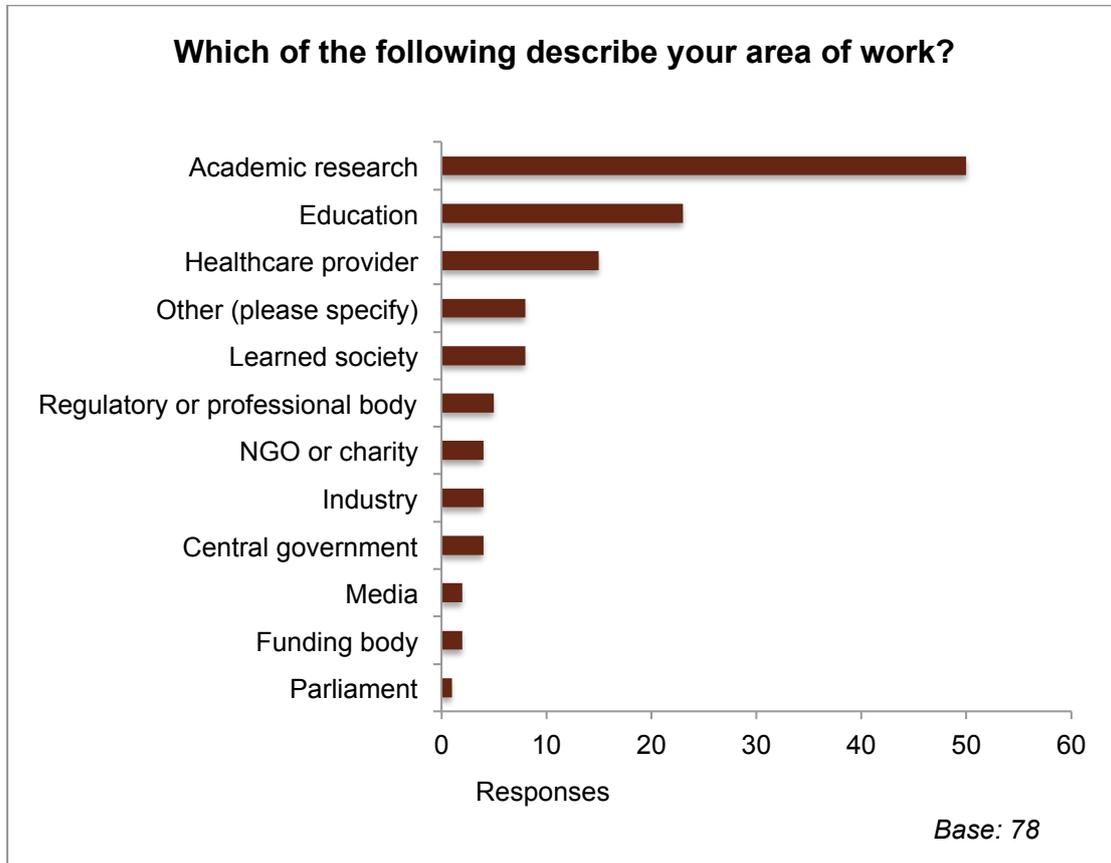
- Via the Nuffield Bulletin, sent to around 100 close stakeholders comprising current and previous Council members, Working Party members and affiliates of the Council (74 responses)
- In the newsletter with approximately 2000 subscribers (17 responses)
- Publicising via the Nuffield Council on Bioethics website (6 responses)
- Publicising via the Nuffield Council on Bioethics Twitter account (2 responses)

Individuals contributed to the survey on a confidential basis, and were asked for their personal experiences with and opinions on the Nuffield Council on Bioethics rather than the views of the organisation they work for. All questions were voluntary, so in some cases the total number of responses is less than 99.

Observations on the sample:

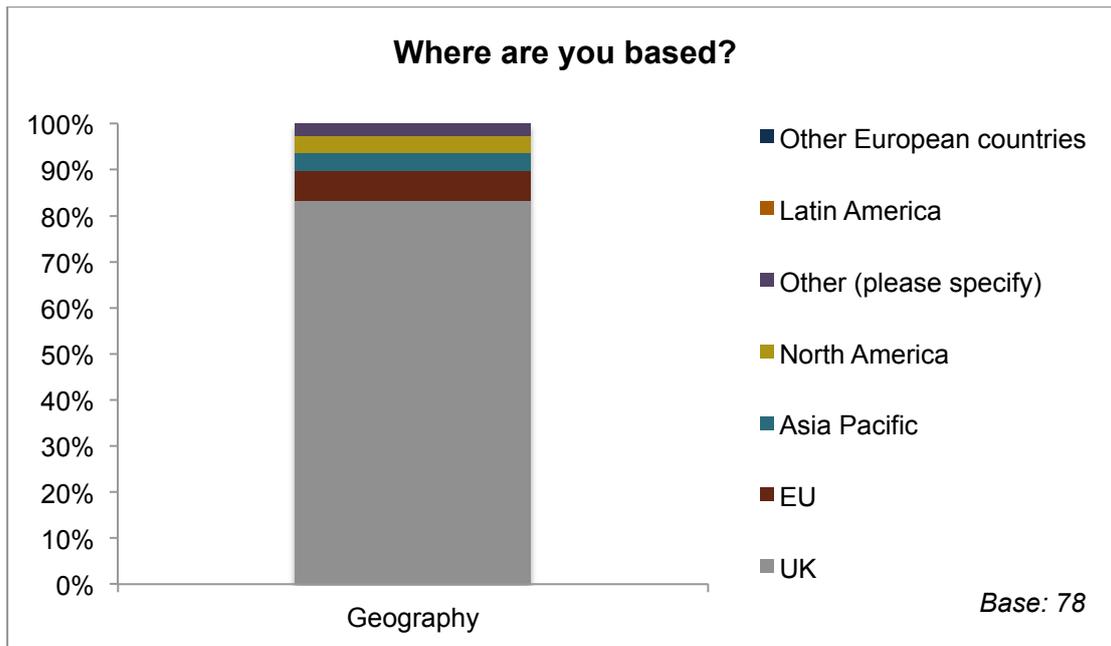
Survey participants were from a range of different backgrounds, but a large majority (50 respondents) described their area of work as academic research. The second largest group (23 respondents) identified education as their field of work.

Figure 1: Survey respondents - background



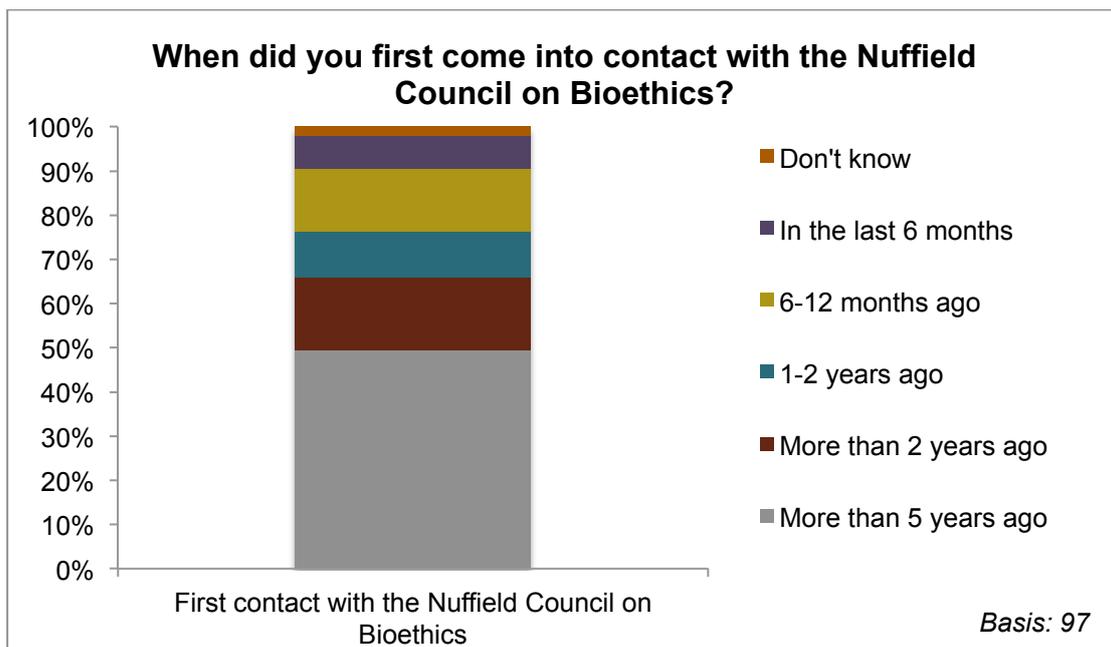
Most of the survey participants were based in the UK, a small number of respondents was based in the EU, North America or Asian Pacific countries.

Figure 2: Survey respondents - geography



Overall, the majority of respondents have known the Nuffield Council on Bioethics for a long period of time; for over 5 years (50%) or over 2 years (17%).

Figure 3: Survey respondents – length of relationship with the Council



Respondents who completed the survey from the Twitter or Website link have generally known the Council for a shorter amount of time than participants who responded to the Bulletin or Newsletter link.

2.3 *Limitations and comments on the process*

Qualitative interviews

Many of the Nuffield Council on Bioethics' stakeholders engaged well with the process. Their participation indicates that the Council has a strong base of stakeholders who are keen to assist and support it as it plans for the future. A number praised the Council for seeking feedback from its stakeholders and several are keen to see the final results of this evaluation.

All of the stakeholders we spoke to had a broadly positive view of the Council. However, many stakeholders did not have extensive knowledge of its internal processes, topic selection processes or the Working Parties. As such, only a small number provided a detailed assessment of the Council's performance against its previous strategy. Several stakeholders mentioned that the Council could be more transparent about these processes.

It is important to note that report does not include the views of any of the Council's three funders.

The other limitations to this evaluation are common to all qualitative evaluations:

- *Confidentiality:* To ensure the evaluation is based on frank and open feedback from interviewees, we are committed to respecting respondents' anonymity. Comments made in the interviews are therefore not attributed to individuals in this report and we avoid including direct comments which would enable an individual to be identified
- *Quantifying data:* With a qualitative exercise of this kind we do not quantify how many people share specific views, instead we offer a guide throughout the report as to whether the views expressed are shared by the majority or a smaller group of interviews. Equally, we consider it important to include some comments voiced by just one or two individuals as these often add to our detailed understanding and the richness of the evaluation. Where comments are voiced in just one interview this is noted.
- *Attribution:* In interpreting the evidence collated and analysed in the evaluation it is important to consider the question of attribution: where progress has been made, to what extent is it possible to attribute this the Nuffield Council on Bioethics' work? Attribution of impact in public policy is by definition more qualitative and less verifiable than impact in other areas. The challenge of attributing impact to the Nuffield Council on Bioethics is exacerbated by the number of organisations providing evidence on or communicating about bioethics as well as media coverage of related issues. These factors cannot be quantified and accounted for in full. Attribution indicated in the evaluation is based on the available evidence, the qualitative element of which relies on partial, external perceptions of the Nuffield Council on Bioethics.

Quantitative survey

The survey captures useful additional perspectives from a diverse community of stakeholders. However, due to the small sample size and the self-selecting nature of that sample, the primary role of the quantitative survey is to validate the findings of the stakeholder engagement. The findings of the survey largely accord with the findings from the interviews. However, any conclusions drawn from the online survey should be caveated accordingly.

3 Stakeholder perceptions of the Nuffield Council on Bioethics

3.1 Relationship with and perceptions of the Nuffield Council on Bioethics

Most stakeholders interviewed during this process have known the Nuffield Council on Bioethics for over 5 years. Some stakeholders have a strong relationship with the organisation and could comment on many aspects of the Nuffield Council on Bioethics, whilst many others only know the Nuffield Council on Bioethics in the context of a single topic or report. Those in the latter category are often only able to comment on a specific report and its development.

Most stakeholders we interviewed found the Council easy to engage and work with. Many claimed to have a good relationship with the Council and enjoyed working with the organisation.

The vast majority of stakeholders interviewed understand that the Nuffield Council of Bioethics is independent and non-partisan. Almost all stakeholders interviewed believe that the Nuffield Council on Bioethics has a high level of credibility. This is perceived to be the result of its academically rigorous report writing process and the reports themselves. To many, the Nuffield Council on Bioethics is a “household name” in bioethics.

Research funder: *“Nuffield's biggest strength is their credibility. They are very independent and rigorous in their approach. This gives their outputs and reports a solid, trustworthy credibility.”*

Policy maker: *“On particular issues they're great. We have a good relationship with them.”*

Media: *“There's just something respected about this agency. People do look at these reports and do wait for these reports.”*

Several stakeholders, including some policymakers, associate the Nuffield Council on Bioethics with a collection of reports rather than an organisation. This was particularly the case for policy makers who do not have a strong relationship with the Council.

Policy maker: *“The body is low key, but their reports are extremely influential.”*

Few of the stakeholders interviewed have worked in partnership with the Nuffield Council on Bioethics or could name an organisation that the Council has collaborated with outside of the report development process.

Stakeholders interviewed from the academic community have a particularly strong relationship with the Nuffield Council on Bioethics. Academic stakeholders who claimed to understand the topic selection process see it as an effective way of defining the important issues in bioethics. Some academic stakeholders interviewed describe the Nuffield Council on Bioethics as “curators of academic opinion” on important issues.

Several policymakers compare the Nuffield Council on Bioethics with other organisations. For a number of interviewees, the Council on Bioethics delivers recommendations with an authority comparable to a government commission or select committee.

Policy maker: *"They have got a good reputation but I wouldn't say they're high profile."*

Stakeholders interviewed from the NGO and private sectors had the weakest relationships with the Nuffield Council on Bioethics. A small number of interviewees from these sectors reported that Nuffield engaged with them well during the working group and report writing process but has struggled to maintain ongoing engagement on their topics of interest.

Global stakeholders speak positively about the Nuffield Council of Bioethics, describing the organisation as a respected actor in the international network. Several perceive the Council to be the leading European bioethics voice and one of the most respected globally. However, one international stakeholder commented that the Nuffield Council on Bioethics does not dedicate sufficient resources to international engagement.

International Stakeholder: *"[The Nuffield Council on Bioethics] has a position of respect in the global community."*

International Stakeholder: *"Nuffield is our primary partner in helping us roll out our materials to our [international] counterparts."*

The respondents to the online survey reinforce this positive view of the work of the Nuffield Council on Bioethics. When asked 'How effectively do you think the Nuffield Council on Bioethics is working towards its objective(s)?', 45% responded 'very well' and 41% responded 'fairly well'.

3.2 Views on the purpose and role of the Nuffield Council of Bioethics

For most stakeholders, the Nuffield Council on Bioethics' key role is to identify important topics in bioethics and bring together the views of experts on these topics. Several stakeholders see the participation of non-bioethicists in the Council's work as a fundamental part of its convening role.

Academic: *"It is not a Council of Bioethics, it is a Council on Bioethics."*

Beyond this, views start to differ, largely based on the individual's definition of bioethics. Several stakeholders compared the Council with academic research bodies working on bioethics. Academic bioethics research is perceived to articulate one opinion on bioethics while the Nuffield Council on Bioethics consults and explains the full spectrum of "rational opinions" on a topic and builds recommendations based upon a consensus of views. When issues are less defined, the Nuffield Council on Bioethics summarises the potential applications of the scientific concept being discussed along with associated ethical concerns.

Academic: *"Academic arguments are intended to persuade and the role of the Council is more to inform. The Nuffield Council on Bioethics is needed in questions about science and its applications."*

Academic: *"The Council takes into account all rational views [in developing report]. Not all views need to be represented. Extreme views held without particular justification don't need to be considered... There is appropriate representation [on the Working Parties]."*

NGO: *"With an academic you are getting one person's perspective whereas the Nuffield Council on Bioethics will be more thoughtful, you see all the people who have been interviewed...so that's very helpful."*

Some stakeholders see the role of the Nuffield Council on Bioethics to be specifically focused on bioethical considerations in biological or medical research. Several of these stakeholders see a direct link between the Council reports and ethical guidelines for specific research projects.

Professional body: *"[The role of the Nuffield Council on Bioethics is] ensuring that there are proper ethical considerations in biomedical research."*

Other stakeholders interviewed perceive the primary purpose of the Nuffield Council on Bioethics to be influencing bioethics policy in the UK, by gathering evidence to inform bioethical debate. Some take this view one step further and liken the Nuffield Council on Bioethics to a national council of bioethics. One policymaker sees the role of the Council's reports as complementing government reports and adding weight to government findings.

Policy maker: *"In the bioethics area the Nuffield Council on Bioethics is the UK's de facto bioethics committee"*

Private Sector: *"They try to take an independent, academically focussed overview of some of the hotter ethical and regulatory issues and try to come up with positions on ways forward. Or they review a subject to say this is an issue of concern. And they aim to provide guidance where relevant."*

The majority of stakeholders interviewed discussed the role of the Council in terms of public bioethical debate. A small number of stakeholders perceive informing public debate on bioethics to be the Nuffield Council on Bioethics' primary role.

International stakeholder: *"To deliver opinions, statements on 'bioethical issues' (in the widest sense of the word) in the field of ethics and natural sciences to the public and politics."*

3.3 Audiences and communications

The Nuffield Council of Bioethics engages with a wide range of groups. Many stakeholders engaged in this process are only aware of a subset of these audiences. Part of the lack of consensus on the role of the Nuffield Council on Bioethics amongst stakeholders, is due to a lack of clarity and understanding of its intended audiences.

The Nuffield Council on Bioethics' audiences can be grouped into the following categories:

- Policy makers – identified by most stakeholders interviewed
- Academics and researchers – identified by many interviewees
- Media and general public – identified by many interviewees
- Professional groups, affected sectors and other interested stakeholders – identified by a small number of interviewees
- International audiences – identified by a small number of interviewees

- Young people – identified by one stakeholder

Over the last 5 years the Nuffield Council on Bioethics has expanded the range of audiences that it seeks to influence. However, many interviewees indicate that the Council is not consistent in the way that it engages with different audiences and this is seen as the organisation's weakest area. Whilst the Council have identified which audiences it wishes to reach, there is no clear objective behind the engagement with different groups. Few stakeholders interviewed are aware of specific objectives or strategies for communicating with audiences outside the policy community. Others feel that the work of the Council is insufficiently tailored to its new audiences:

NGO: *"It is a shame that [the Nuffield Council on Bioethics] is so policy focused and so academically written ...the conclusions and recommendations could be better written for the audience."*

Learned society / Professional body: *"Their reports are dense so to read them from cover to cover is a huge commitment. In fairness they do try to help with that with headings, numbers paragraphs...but 200 pages is quite a commitment."*

Engaging with policy makers:

Most of the stakeholders interviewed reported that the Nuffield Council on Bioethics engages well with policymakers, ultimately to encourage them to use conclusions from the Council's reports. One indicates the Council on Bioethics could take an even more direct approach:

Policy maker: *"They could do more to let relevant organisations know about them."*

Private sector: *"They do a 300-pager, 20-pager and one-pager. I'd still like to see a half-pager with a lower reading age that goes to MPs."*

A number of stakeholders commented that the report development process lacks flexibility, making it difficult for the Nuffield Council on Bioethics to align the timing of publishing a report with upcoming policy reviews, research funding reviews or other important moments of for the organisations it seeks to influence. One policymaker reported that a recent report had only limited impact because it was published and communicated at the 'wrong' stage in their policy review cycle.

Engaging with broader audiences

Over recent years, the Council has increased investment in engaging with broader audiences; a small number picked up on this. Several commented that the report summaries have made the Nuffield Council on Bioethics findings accessible to wider audiences, though some feel that even shorter summaries would give the Nuffield Council on Bioethics access to an even wider audience. Most were less aware of the Council's work with interest members of the general public and a number question to what extent this should be a primary goal for the organisation.

Research funder: *"Nuffield's primary audience is the civil service and politicians, and scientists in the field ... I am not sure that it is Nuffield's role to focus on the public and public debate"*

Media: *"Nuffield's objective is to inform public debate around key areas of bioethics"*

Policy maker: *"The reports are aimed at the public, general public, but the people who make most use of the reports are politicians, bureaucrats, organisations and scientists. The issues that they pick up are things the public (through the media) are interested in."*

Media and social media engagement

Media stakeholders report good working relationships with the Council and note its input is relevant to their readers or listeners.

Media: *"They are engaging, they talk about issues in an interesting way and not in a dull, white-lab-coat way. That is a really important asset."*

Media: *"The reports are fine for science journalists, they do not need things dumbed down. They are nicely suited to intelligent journalists."*

Media: *"If [an Nuffield Council on Bioethics report release] is not covered it is because the media are not interested, not because they haven't tried."*

However, they are unsure of the Nuffield Council on Bioethics' overall strategy for engaging the general public. One media stakeholder observed that the Nuffield Council on Bioethics often struggles to explain the expected impact of a report to journalists.

At present, the Nuffield Council on Bioethics invests only limited resources in social media. A small number of stakeholders commented that its social media activity is low, but suggested that many of its audiences are not active social media users. There are currently similar numbers of people signed up to receive the Council's newsletter (3,900) as Twitter followers (4,260).

3.4 Other actors in the landscape

For most stakeholders interviewed the Nuffield Council on Bioethics does not have direct competitors or peers in the UK. Many referred to the work of the Royal Societies, Royal Academies and think tanks that occasionally cover similar topics to the Nuffield Council on Bioethics. For most, this overlap is limited. Stakeholders do not regard the Council's international peers (including the Presidential Commission for the Study of Bioethical Issues, the Council of Europe and the German National Ethics Council) as competitors, as these bodies do not write for a UK audience.

Although there is no obvious direct competitor to the Council, stakeholders identify a range of other actors who operate in and impact on the sectors in which the Council works.

Views on who these other actors are is, inevitably, influenced by stakeholders' definitions of the landscape in which the Council operates. Stakeholders interviewed can be broadly categorised into two groups in terms of their description of this landscape. For the first, the bioethics sector primarily consists of academics and policy makers. Stakeholders in this group are less likely to suggest that the Council needs to broaden the audiences it engages with. The second group views the sector more broadly and also considers bio-medical industries, professional groups and civil society groups to play an important role within it. Stakeholders using this definition were more likely to call for the Council to take a more inclusive approach.

Each of the groups of actors detailed below are identified by multiple stakeholders.

- **Policymakers** – The majority of stakeholders interviewed considered policymakers to be central to the bioethics landscape and many viewed policy makers as the ‘customers’ of bioethics research (including the Council’s work.) A small number of stakeholders commented that the relationship between policymakers and scientists has historically been characterised by mistrust. However, a small number feel this is improving and one says this relationship is now the strongest it has been for 20 years.

Policy maker: *“Politicians by and large tend to mistrust experts. They take scientific advice of course and listen to bodies like the Royal Societies and colleges and the Nuffield Council, but are always suspicious of special pleading.”*

- **University bioethics departments** – Most stakeholders report that the number of bioethics departments in UK universities has grown over the last 20 years, though there is no clear consensus on whether this growth will continue. Several stakeholders describe differences between academic bioethicists and the Council. A number suggest that academic research often has an underlying perspective or “an agenda” whereas reports from the Council represent unbiased summaries of a range of opinions. As such, University bioethics departments are not seen as competitors of the Council.
- **Royal Societies, Royal Academies and other professional bodies** – Unlike the Nuffield Council on Bioethics, the Royal Societies and Academies are seen to represent a particular group of scientists or professionals. Several stakeholders observe that they produce reports with bioethical elements but that these are rarely the focus of these bodies’ reports.
- **Think tanks and consultancies** – A small number of stakeholders mention think tanks or consultancies who occasionally research or lobby on bioethics topic when there is a cross over into issues relevant to their organisations. The King’s Fund is the only think tank that is referenced by a significant number of stakeholders in this context. One stakeholder perceived the King’s Fund to have a higher public and political profile than the Nuffield Council on Bioethics, adding that it also has a stronger political agenda. The King’s Fund is much larger than the Nuffield Council on Bioethics and has an annual spend of over £15m. A small number comment that the Council could learn lessons from the King’s Fund’s use of events to engage interested members of the general public.
- **Research councils** – Many of the stakeholders interviewed see research councils as key actors in the bioethics landscape given their authority over research spend. The Medical Research Council (MRC) and the Biotechnology and Biological Sciences Research Council (BBSRC) are mentioned most frequently. Some stakeholders describe the research councils as a specific target which the Nuffield Council on Bioethics seeks to influence.
- **Other funders of research** – The Wellcome Trust and Nuffield Foundation were the most frequently mentioned philanthropic funders of bioethics. These funders have a key role in the application of bioethics in research. Several stakeholders also see

these funders as an audience for the Council's reports. One interviewee indicates that these Funders use the Council's reports to support their decision making.

Private sector: *"There's a big internal audience for their work within their funders. MRC would have to do it themselves if the Council didn't. I think MRC and the Wellcome Trust are doing some of the same work."*

A small number of other bioethics funders are identified by individual stakeholders, including: the Esmée Fairbairn Foundation, Nesta, The Health Foundation and DFID (for bioethics in the development sector).

- **Industry** – Many stakeholders commented on the growing role of the private sector in bioethics. The industries most commonly referenced were life sciences and technology. Some stakeholders saw the private sector as a group of actors who are affected by bioethical policy. Others observe private sector organisations driving the bioethics agenda, through new technological development.
- **Ethical lobbying groups** – Several stakeholders discuss the role of lobbying groups in bioethics. One policymaker explained that lobbying groups often receive greater attention than the Nuffield Council on Bioethics, but do not have as strong a reputation. Another stakeholder voiced concerns that policy makers may not distinguish between lobbying groups and independent councils. The Scottish Council on Human Bioethics is given as an example of an organisation that could appear to be unbiased but was said to be driven by a subset of ethical viewpoints.

International country-level councils – A small number of stakeholders interviewed were aware of bioethics actors outside of the UK. The German, French and US bioethics councils were most commonly described as being world leading, alongside the Nuffield Council on Bioethics. Several international stakeholders perceived the bioethics community to be globally connected but still nationally focused. Several stakeholders report that the Nuffield Council on Bioethics' non-governmental status sets it apart from some of its international peers. A number of interviewees also consider the Council of Europe to fall into this group of actors. One stakeholder identified the Hastings Center, a US based independent bioethics research institute, as Council's closest international peer.

3.5 State of the sector

Defining bioethics

Among the stakeholders interviewed, there is no single accepted definition of bioethics or the bioethics sector. For most, bioethics is restricted to the ethics of biological and medical research. Others consider its definition to be broader and include topics such as climate change, culture and epidemics in their descriptions.

A number of academic interviewees also discussed the scope of "bioethics policy issues" as a subsection of the broader field of bioethics. This includes topics with ethical considerations for policy makers specifically (as opposed to for researchers, other decision makers or private sector organisations).

International stakeholder: *"The scope of bioethics is huge."*

Bioethics topics

In general, stakeholders tended to divide issues within the bioethics landscape into three categories:

- **New topics** - which emerge as a result of new science or a new technique requiring ethical consideration (e.g. new biotechnologies)
- **Changing topics** – these are not new issues but instances of new ethical considerations arising from new technological or scientific developments (e.g. bio-data)
- **Public and political attitudes questions** – again, these are not new topics and are not linked to new questions. These are questions which may change as political and public attitudes around particular ethical issues evolve over time (e.g. abortion or euthanasia.)

Interest in bioethics

The majority of interviewees think that bioethics is now more important than ever but many say this is not reflected in levels of funding for bioethics. Several academic stakeholders mentioned that the bioethical elements of research are often not funded by research grants.

Several stakeholders commented on private sector funding for bioethics research. Whilst some believe this to be one of the few growing sources of bioethics funding several interviewees, including those from within the private sector, questioned whether this is an appropriate source of funding. A small number felt that this could be acceptable in specific and limited circumstances, under carefully structured terms and conditions.

A number of stakeholders identified growing interest in bioethics in Government. One stakeholder saw an emerging need for increased independent bioethics advice to government, following a reduction in scientific advisors during recent spending cuts. Another said that the impact of civil service reform and the open policy making agenda also may also result in greater demand from the government for bioethics research.

Several interviewees believe that public interest in bioethics has increased over the last 10 years. One media stakeholder specifically mentioned the rise of science journalism and how this has provided a platform for increased discussion of bioethical issues in the media. Another reported that there is a topic related to bioethics “in the news almost every day”. Stakeholders’ views on whether bioethics is a priority in science journalism vary. One interviewee reported that bioethics is often a side element in science media stories. Another believed that most science debates in the media are really bioethics debates.

Few interviewees express detailed views on the role of bioethics in education. However, one stakeholder suggests the role of bioethics in education has peaked and that the current focus on pure science in the national curriculum could limit engagement on bioethics in schools.

Private Sector: *"Bioethics is emotive, it's interesting, it's relevant to our society's future. I just love it."*

Private Sector: *"I think bioethics is a live issue, especially when you think about data."*

Media: *"Within journalism, ethics often ends up being second fiddle."*

3.6 The future of the sector

Stakeholders do not anticipate major changes in the bioethics landscape in the short term. Most stakeholders interviewed think the importance of bioethics will remain constant or increase in the next 5 to 10 years.

Policy maker: *"I suspect [bioethics] will become more important. Public interest in ethical questions will become more important... It certainly won't go away and will intensify if anything"*

A small number of stakeholders commented that bioethics will affect an increased number of organisations in the future, such as those within the growing data science sector. Other stakeholders interviewed, particularly those from outside the UK, expected the future of bioethics to be more international. In particular, they identify opportunities for greater collaboration between bioethics organisations on globally relevant topics.

International stakeholder: *"The future of bioethics will be much more international. The most important issues will be cross-border issues, such as big data, storage of information across country borders, health data etc."*

Others foresee a more challenging future for bioethics. Some stakeholders identify specific bioethics topics that will increase in importance. These include data, genetics, synthetic technology, artificial intelligence and nanotechnology. A number refer to long standing ethical issues which they say will remain interesting and relevant, including abortion and animal welfare.

A number of stakeholders are concerned that bioethics could be 'forgotten' if the sector does not demonstrate its importance. Several stakeholders mention funding cuts in research and believe that it will be increasingly important to ensure researchers adhere to bioethical principles when there may be a temptation to 'cut corners'.

3.7 The Nuffield Council on Bioethics' geographical scope

Since the creation of the Nuffield Council on Bioethics, the organisation has primarily focussed on developing reports consolidating UK perspectives on bioethics to inform UK discourse. Most of the Nuffield Council on Bioethics' stakeholders understand and agree with this focus. A small number comment that UK focussed reports maximise their impact on UK policy and society.

A limited number of the Council's reports have considered more international bioethical subjects, such as the report on 'Children and clinical research'. The report on 'The ethics of research related to healthcare in developing countries' has an international focus. However, one international stakeholder questioned whether these reports have enough input from international representatives to be able to draw internationally relevant conclusions.

International stakeholder: *"Nuffield Council on Bioethics resources are UK focussed and not culturally relevant from [our] perspective"*

Despite the Nuffield Council on Bioethics' UK focus in its reports, the international stakeholders interviewed feel that many of its reports were relevant and useful to them. Stakeholders indicated that the geographic scope of the Nuffield Council on Bioethics' impact was greater than the geographic scope of its inputs.

To some extent, the Nuffield Council on Bioethics' UK focus is a reflection of its funding and governance structure. The Nuffield Foundation, the Wellcome Trust and the MRC all have a predominantly UK focus in their funding. The Council could broaden its international focus and dedicate more resources to this, but may need to explore additional source of funding to support this.

Similarly, most of the Council members and other key contributors to the Nuffield Council on Bioethics reports have more experience on UK focussed bioethics. To become truly international, the Nuffield Council on Bioethics would need to build relationships with more international bioethics stakeholders.

International stakeholder: *"Nuffield Council on Bioethics has a position of respect in the global community.... but could take a greater role on the world stage"*

4 Performance against 2012-2016 strategy

In 2011/2012, the Nuffield Council On Bioethics undertook a strategy review and produced a strategy document for the period 2012-2016. This document laid out the organisation's mission, aim and objectives, values and priority areas. These priority areas are to ensure that:

- It has a diversity of input into its work, ensuring that as wide a range of people as possible are able to contribute.
- It has a wide reach so that both the policy impact and the promotion of public debate are maximised.
- It maintains a range of activities so as to better inform and engage a wide range of audiences.
- It is as transparent as possible so that it is clear to stakeholders how the Council operates and how to interact with it.
- It has appropriate ways of evaluating its own quality, reach and impact.
- It has reporting and governance arrangements in place that support these aims.

From the internal documents that were shared for this review and the perspective of the external stakeholders interviewed, the Council appears to have made some progress in each of these areas. However, as the 2012-2016 strategy does not set ambitious, measurable targets for the organisation, an evaluation against the strategy document alone would not give a full picture of the Council's success, challenges or progress. Progress is noted against many of the objectives in the strategy but, due to the nature of the objectives, this monitoring predominantly tracks effort rather than results.

The Nuffield Council on Bioethics' leadership have more ambitious goals for the organisation, but these are largely undocumented. The Council's report writing process is also central to its approach, but not explicitly mentioned in the strategy document. Many strategic decisions are made on the basis of preserving the credibility this process. The Council's progress and achievements in areas outside of the scope of the 2012-2016 strategy are covered in other sections of this report.

Among the Council's stakeholders who contributed to this review, awareness and understanding of the strategy was very limited. For the most part, stakeholders regard the Council as an established body, which demonstrates consistency in its approach and the quality of its outputs. However, few see evidence of a strategy or believe the organisation is changing.

However, stakeholders do comment on a number of the priority areas set out in the 2012-2016 strategy.

- **Diversity of input:**
Stakeholders broadly perceived the range of academic views in the working groups and forward look meeting to be diverse and comprehensive. Several commented that there are few non-academics on the Council, working groups or at the forward look meeting and called for increased diversity in the types of roles represented in the meetings.

Although it does not set specific targets for diversity of input, the Council's progress reports highlight progress made in increasing diversity of input to its work. There have been a number of recent developments in this area including:

- Appointments to the Council including academics from a non-science background individuals who are employed outside education
- Inclusion of individuals from industry and practitioners in relevant fields in the working groups
- An open invitation via the website, newsletter and social media networks to submit ideas for work that the Council should pursue (responses to this have been relatively low)
- An open invitation to express an interest in joining a working group (responses to this have been relatively low)
- Consultative activities outside committee membership, such as a survey of 1000 scientists for *'The culture of scientific research'*.

For the most part, stakeholders interviewed in the review do not appear to be aware of these specific developments.

- **Wide reach:**

The Nuffield Council on Bioethics reaches a wide range of audiences both across sectors in the UK and among bioethics groups globally. In 2014, the Council:

- Was mentioned in over 60 articles in the UK and international media
- Had 5 broadcast interviews in the UK and internationally
- Received over 173,840 visits to the website and nearly 364,800 page views
- Had 4,260 followers on Twitter
- Was 'liked' on Facebook over 730 times
- Had over 3,900 people signed up to receive its bimonthly and other newsletters.

In 2013 the Council's website had over 100 visitors from each of 70 countries (*source: the Nuffield Council on Bioethics 2014 report*).

These metrics demonstrate that Council is reaching audiences in the UK and internationally.

- **Range of activities:**

Most stakeholders feel that the Council organises its work and resources around the development and publication of reports and many feel that this is the right approach. Others believe that it should invest more resources in engaging with relevant audiences and disseminating its work.

The Council does have a range of engagement activities for audiences beyond academics and policy makers. The Council's activities for broader audiences include the following:

- The Cheltenham Science Festival
- Debating Matters competition
- Second series with FunKids radio
- Annual public lectures
- Talks for secondary school and undergraduate students

Most stakeholders interviewed were not aware of any of these activities. A challenge for the organisation, going forward, is to better incorporate these broader activities into the organisation's core ways of working.

The Council is aware of this challenge and there are some early examples of progress in this area. The research for '*Children and clinical research*' report involved engagement with children, young people and parents through direct consultation, the Youth-REC project in Brighton and the Chocolate trial in Wimbledon.

Two new roles have been created since 2012 to enable the Council work more flexibly across its core process and work in partnership with others, though no stakeholders interviewed could comment on the specific impact of this.

- **Transparency:**

Most of the Nuffield Council on Bioethics' stakeholders believe that the organisation is sufficiently transparent. A number comment that transparency is particularly important for the Council given the nature of its work. However, detailed understanding is limited and few felt able to offer informed comments on this aspect of the Council's work. Several stakeholders were unclear on how individuals are selected for working groups and committees.

In contrast to the majority view, one policy maker mentions that the Council's report writing process is less transparent than for government reports, which were often used as a comparison by stakeholders given the perceived authority of the Council's output. As discussed earlier in this report, some stakeholders find the reasons for topic selection unclear.

In recent years, the Council has increased the number of 'internal' documents that it shares in the public domain. The following are now publically available:

- The topic selection process
- Future topics being considered
- A governance map of the organisation and its committees
- 2012-2016 strategy and 1992-1999 review
- The names of working party members for each report
- Terms of reference for reports
- Description of the external consultation and consultation responses for reports
- Responses to call for evidence for reports
- Launch seminar presentations for reports

However, very few stakeholders interviewed for this review had noticed the Council's focus on increasing transparency.

- **Evaluation of quality, reach and impact:**

The Council captures data on citations, event references and media references to its work in the UK and internationally. Its annual report contains a section on the 'year in numbers' that highlights key metrics including the number of reports published, active

working parties, consultations held, media coverage, events attended by the Council and website statistics. Some of the statistics collated, such as presentations at conferences and events, paint a clear picture of impact whilst others do not give an indication of the quality, reach or impact of the Council's work. The organisation also reports on the qualitative impact of its reports.

Again, external stakeholders did not provide a detailed assessment of the organisation's evaluation capabilities.

- **Reporting and governance:** The Nuffield Council on Bioethics provides annual impact reports to funders and quarterly updates to the Council. As no funders were engaged in this evaluation, it is not possible to assess the quality of this reporting in the context of this review.

The organisation's governance is made up of the Council (which meets quarterly) and a number of subgroups. Most of the subgroups are made up of a subset of Council Members, but a number also have external members. The 2012-2016 strategy calls for minor additions to the current governance, rather than any substantial change. Since 2012, the Council has increased the number of subgroups and level of written and in-person communications with its funders. The new Management and Risk subgroup has developed new policies such as guidelines for working in partnership with others.

External interviewees were not aware of these changes and were unable to assess the organisation's reporting and governance.

During the interviews, we asked stakeholders to reflect on the quality of the Council's work. 'Quality' is referred to in the organisation's 2012-2016 strategy, but as a value rather than a priority area.

- **Quality:** The Nuffield Council on Bioethics' reports are widely and unanimously understood to be high quality and academically rigorous. These reports were cited in 538 academic journal and publications in 2013. For several academics interviewed these measures are an indication of the reports' quality.

Most stakeholders regard the Working Party members to be the academic leaders in a given topic, which gives further weight to the Nuffield Council on Bioethics reports. Several stakeholders attribute the quality of the Council's reports to the strength of the working groups.

Nuffield reports are often over 200 pages long and have accompanying summary and recommendation documents. Many stakeholders question whether the high quality academic style of the full reports limits their influence on non-academic audiences, in particular, non-scientific policymakers, the private sector and NGOs. However, most also recognise that it is the academic rigour behind the reports that guarantees their credibility. Some discussed whether it was possible to retain the rigour of the process whilst creating more accessible outputs.

5 The Nuffield Council on Bioethics' current and anticipated impact

5.1 Introduction

Conversations with stakeholders provide detailed insight into the perceived impact of the Nuffield Council of Bioethics' work and make clear the need for consideration of how impact can be determined and to what ends.

This section provides information on:

- *Stakeholders' perceptions of the Nuffield Council on Bioethics' impact*
- *Perceptions of the Council's impact amongst from the quantitative survey*
- *Factors limiting the organisation's impact*

5.2 Stakeholders' perception of impact

Stakeholders discussed their views on the impact of the Nuffield Council on Bioethics readily and without prompting. For the most part, stakeholders perceived the Nuffield Council on Bioethics to be making either a sufficient or a significant impact. As the Nuffield Council on Bioethics engage with several audiences for different purposes, impact should be assessed within the framing of audiences.

The most commonly discussed example of impact was on policymakers. The level of impact achieved varies by topic, determined by how relevant the topic is to current policy questions. However, this appears to be at least partly due to the higher profile of work that reaches parliament.

The report on *'Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review'* is reported by many stakeholders to have had the most impact recently. Several policymakers believe that this report had a direct and significant impact on the government's decision to allow mitochondrial replacement. A media stakeholder commented that it would be difficult to identify a debate about mitochondria replacement where the Nuffield Council on Bioethics was not mentioned. A small number of stakeholders mention that the *'Ethics of research involving animals'* and the *'Public health: ethical issues'* reports also influenced parliamentary policy decisions:

Policy maker: *"In the mitochondria debate: if the Nuffield Council on Bioethics had said that it is likely to be an unethical practice, it would have been hard to get [the bill] through... The one on animals in research was also very good... I'm sure it influenced David Sainsbury. It clearly had an impact"*

Policy maker: *"[the 'Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review' report] was enormously important in parliament ...[On bioethics topics] we consider there to be two reports: the official one and the independent Nuffield Council on Bioethics one."*

Policy maker: *"When the Nuffield Council on Bioethics produces a report, people [policymakers] rely on that... they are influential, but go about it in a quiet way... It is recognised [in Westminster] and reports are often quoted".*

Many of the Nuffield Council on Bioethics' reports continue to be used for several years after their publication. As such, much of the Council's demonstrable policy impact does not occur in the short term. One stakeholder expects the *'Novel neurotechnologies: intervening in the brain'* report to have policy impact in the future. Another stakeholder comments on the time that the *'Public health: ethical issues'* report took several years to affect policy, largely due to slow moving government processes.

Policy maker: *"The public health report eventually led to a ladder of interventions ...it made its way into Government white paper on public health. It was almost reproduced in there."*

Academic: *"Nearly always they are not followed rapidly by legislation, they just help to shape the way legislation and cultural norms develop in the years ahead."*

The Council's impact on academic bioethics is perceived to be significant by all academic stakeholders interviewed during this process. One stakeholder comments that although the Nuffield Council on Bioethics does not seek "pioneering findings" of its own, it drives academic thinking on bioethics by giving credibility to the topics it reports on and creates frameworks that shape the focus of academic bioethicists and those working on research with a bioethical component.

Academic: *"The Nuffield Council on Bioethics is a source of identifying what the important issues are. We reference Nuffield Council on Bioethics on issues to demonstrate that it is an important issue."*

The Nuffield Council on Bioethics' impact on professional and research practice appears less direct. The Council does not have any direct authority to influence practice in these areas. However, the Nuffield Council on Bioethics is felt to influence practice through learned societies and professional bodies.

Several stakeholders report that the Nuffield Council on Bioethics has an influence on learned societies and professional bodies that influences practice in the long term. The report on *'The culture of scientific research'* is expected to make an impact on research in the future.

Policy maker: *"I think they do impact on research practice. The one on mitochondria clearly has been helpful on mitochondria disease. The one on data will impact how researchers use data and will impact clinical practice too".*

Learned society / Professional body: *"As a doctor, if you wanted to look at medical ethics you would look at BMA standards. But if you wanted to have a more reflective view of what is going on, the Nuffield Council is the first place to look at"*

A small number of stakeholders perceive the Nuffield Council on Bioethics to be influencing research funding decisions that statutory and independent funders make. One research funder uses the Council's work to validate research funding decisions. One academic who has worked closely with the Wellcome Trust and MRC, reports that they also take the work of Nuffield Council on Bioethics into account when making funding decisions.

Learned society / Professional body: *" They influence researchers by influencing funders"*

The Nuffield Council on Bioethics' history of engagement with the private sector and NGOs is more limited. Nevertheless, several pharmaceutical stakeholders report that they take the Nuffield Council on Bioethics reports very seriously, in comparison with other research, or reports from other think tanks and research bodies. One interviewee described how the reports of the Nuffield Council on Bioethics are an important part of their licence to operate:

Private Sector: *"In any new area of technology - stem cells, cell therapy, gene therapy, data, access to genetic information, trials on children, trials in the developing world - we need to understand the ethical issues to do our work. [The private sector] needs a licence to operate in these areas, so if Nuffield say things that affect that, then we need to pay attention...I take their projects very seriously...They have a higher, better reputation than other academic groups."*

Interviewees also describe how the private sector and NGOs are also influenced by the Nuffield Council on Bioethics indirectly, through the impact it has policy level.

The Council's impact on the general public's attitude towards bioethics was thought to be difficult to measure. To some extent, media mentions on bioethics can be used as a proxy to measure public interest. The number of references to bioethics in the media has increased in the last 5 years. One media stakeholder believed that this is part of an overall increase in the number of science stories in the media. However, another media stakeholder interviewed perceived most science questions in the media to be interesting due to the bioethics questions in the science. Several media stakeholders interviewed regarded the Nuffield Council on Bioethics to be the primary source for quotes in the field of bioethics. Whilst credit for changing public attitudes cannot be directly attributed to the Nuffield Council on Bioethics, the quotes and input provided to the media by the Nuffield Council on Bioethics give the public a more balanced view of bioethics debates.

Learned society / Professional body: *"They seem to get a fair amount of media coverage which gives you a proxy indicator of the interest that is generated and they seem quite well respected and known among some of their target audiences"*

For the last 12 years the Nuffield Council on Bioethics has engaged with children and young people through producing resources and collaborative projects for young people. Only a small number of stakeholders engaged in this process were aware of this aspect of the Council's work. They report the education resources to have an impact on the small number of students who use them. Further research is needed to determine the impact of this.

Despite its UK focus, some stakeholders felt that the Nuffield Council on Bioethics has an impact on national level policy in other countries, and the international policy of global organisations. One international stakeholder comments that the *'Public health: ethical issues'* report was used to develop their organisation's international ethics guidelines. Another international stakeholder also reports that they have used Nuffield Council on Bioethics reports, including the *'Novel neurotechnologies: intervening in the brain'* report in local bioethics discussions.

International: *"They might not know this, but many people in [my country] look at Nuffield's' documents... The report on public health ethics Nuffield's work on neuroscience and brain science has been very influential on our own work."*

International: *"The Nuffield Council of Bioethics has impact on our work in different ways. It is a resource body, both in terms of content of the reports and as a pool of experts. Sometimes the reason*

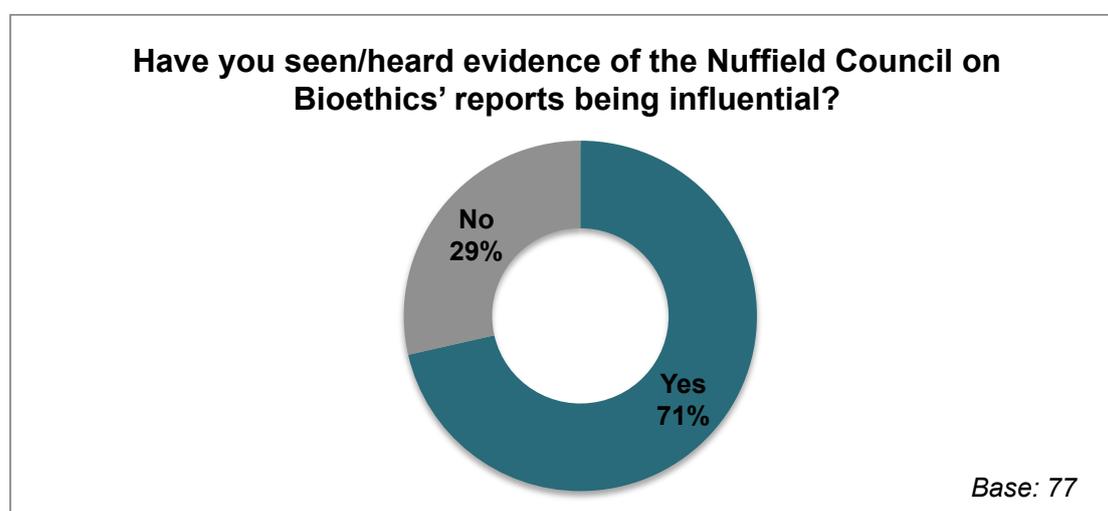
we invite experts is because they have participated in a Nuffield committee or report. Nuffield provides a forward look on how to approach issues."

5.3 Indicators of impact from the quantitative survey

Findings from the quantitative survey broadly support the perspectives of the stakeholders interviewed. As outlined earlier in the report the views of the survey participants are influenced by their role, sector and relationship with the Nuffield Council on Bioethics. 65% of survey respondents engage in academic research as part of their role and 50% have known the Nuffield Council on Bioethics for over 5 years.

When asked if they have seen or heard evidence of the NOCB reports being influential, the majority of respondents responded positively.

Figure 4: Survey respondents – evidence of influence



A significant number of respondents shared specific comments to explain their responses further:

Academic *"I do not know of any report that has not had some impact."*

Academic / Education: *"They are frequently cited as authoritative -e.g. the reports on bioinformation, solidarity, dementia and public health. They've set the terms of the debate in these topics."*

NGO / Education: *"I work in a different sector and have not seen the applied outcome of the Council's work"*

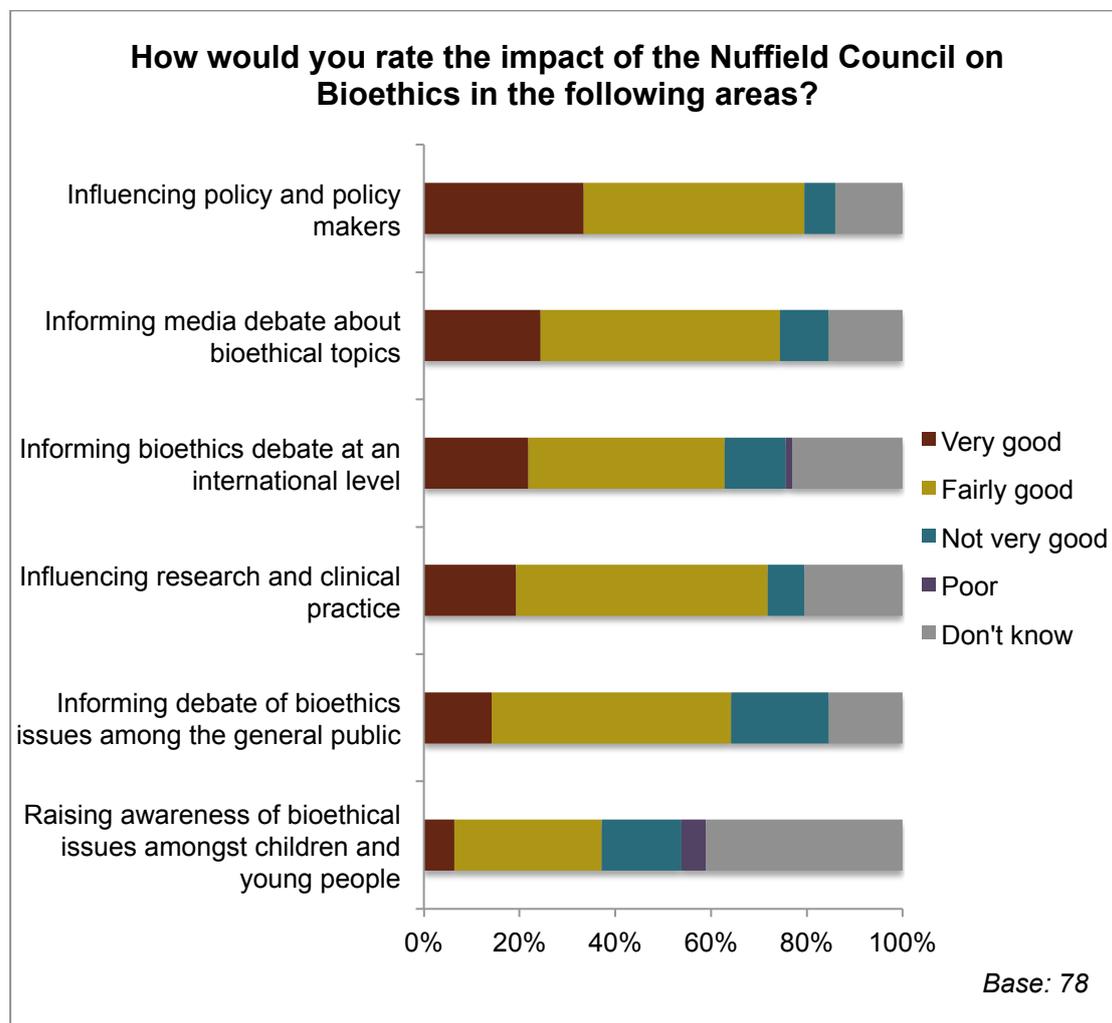
Collectively, stakeholders cited a number of reports that have influenced their work. These include:

- *Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review*

- *Medical profiling and online medicine: the ethics of 'personalised healthcare' in a consumer age*
- *Biofuels: ethical issues*
- *Children and clinical research*
- *Genetically modified crops: the ethical and social issues*
- *Critical care decisions in fetal and neonatal medicine: ethical issues*
- *The culture of scientific research*
- *Biological and health data*
- *Dementia: ethical issues*

As in the qualitative interviews, survey respondents were also asked about the impact of the Nuffield Council on Bioethics' work in a number of areas:

Figure 5: Survey respondents – impact by area



Respondents see the Nuffield Council on Bioethics' biggest impact as being on policy and the media. These are also two of the most visible areas to individuals working outside the sector.

63% of survey respondents indicate that the Nuffield Council on Bioethics also has an impact at an international level. Comments evidence on both academic research and on policymaking.

International policymaker: *"At governmental policy tables and international fora, the Council's work is considered the place to look for in terms of analysis. We'll say "What has the Nuffield Council done in this area?" It is often the starting point for further policy development.... The Council's work has been used to justify policy directions at both the national (i.e. not UK) and international level."*

72% of survey respondents say the Nuffield Council on Bioethics has an impact on research and clinical practice. The reports on 'Children and clinical research', 'Dementia: ethical issues' and 'The culture of scientific research' are perceived to be prompting change in these areas.

64% of respondents feel that the Council informs debate of bioethics issues among the general public, in contrast to the stakeholders interviewed. One stakeholder comments that the general public are a difficult audience to influence with the limited resources available at the Nuffield Council on Bioethics.

Only 37% of respondents perceive the Council to be influencing children and young people. This is consistent with feedback from the stakeholders interviewed. Few survey respondents are aware of any work this audience or see it as part of the organisation's role. A significant proportion of the stakeholders who shared more positive views on impact of engagement with children and young people are from non-academic backgrounds.

Academic *"Fairly good on all counts except the children and young people one which frankly I don't know about - undoubtedly an important function but one that is perhaps separate from mainstream activity which is (or possibly should be) more keyed into the policy process. The Nuffield Council on Bioethics can't do everything."*

Academic / Education: *"If the Nuffield Council provides good materials then some of the dissemination (e.g to young people) is better done by the experts - like teachers using materials in A level ethics/RS classes (e.g. on genetic testing, GM food, behavioural genetics)."*

5.4 Limitations to the Nuffield Council on Bioethics' impact

It is clear that the Nuffield Council on Bioethics is having a broad impact with a number of different audiences. However, seeking precise attribution of this impact presents challenges. Some of which are outside of the Nuffield Council on Bioethics' control and other are factors that the Council could address.

- **Audiences**

As a non-governmental organisation with no formal statutory authority, any response to the Nuffield Council on Bioethics' recommendations on a given topic is discretionary.

Policy maker: *"The Nuffield Council on Bioethics is not a key stakeholder that we need to keep on side... but we do take the Nuffield Council on Bioethics' recommendations seriously."*

Policy maker: *"Sometimes they write recommendations like a select committee, even though they do not carry this authority"*

Whilst the Nuffield Council on Bioethics' credibility gives it influence over individuals who are interested in bioethics, the reports are less likely to be read by individuals who do not think that bioethics are important. The Nuffield Council on Bioethics has chosen not to 'lobby' for its recommendations and stakeholders do not see any the Council engage in any significant 'lobbying' or 'advocacy' for the use of its reports. Several stakeholders interviewed consider the organisation to be 'preaching to the converted'. This approach limits the behaviour change that the Nuffield Council on Bioethics can create amongst broader audiences, though it is not uncommon in organisations aiming inform debate without having a political agenda,

International stakeholder: *The Nuffield Council on Bioethics is "preaching to the converted." The question is, are those who are not interested in bioethics interested in what it says."*

Whilst the academic style of the reports brings the Council credibility amongst many of its audiences, some stakeholders believe that its style limits the impact of Nuffield Council on Bioethics' work on non-academic audiences. Many stakeholders interviewed believe the impact of the Nuffield Council on Bioethics reports would be greater if the findings were explained in a less academic style. This applies to non-scientific policymakers, the private sector and the general public.

NGO: *"[For the report I was consulted on] I do not think there was any impact at all ...it was such a great report but the recommendations were communicated in an inaccessible way."*

The impact of the Nuffield Council on Bioethics education resources is significantly limited by the limited role of bioethics in the UK national curriculum. One stakeholder interviewed anecdotally reports that young people engage well in bioethics debates in schools and are interested in the area. However, another stakeholder believes that few teachers have time to utilise education resources that fall outside of the national curriculum. The decreasing importance of Religious Studies and increased focus on pure science in the latest national curriculum may limit the role of bioethics in education. Whilst the current role of bioethics in education is external factor limiting the demand for the Nuffield Council on Bioethics resources, the Nuffield Council on Bioethics approach to reaching young people is not likely to impact large audiences.

- **Indicators**

The Nuffield Council on Bioethics seek to influence each of its audiences in different ways. Impact needs to be considered separately for each of these audiences. For example citations in journals and publications can be used as a proxy to measure the credibility of the Nuffield Council on Bioethics in the academic community, but this would not be an effective measure of impact amongst the private sector or policy makers. With such a wide spread of different audiences it is difficult to quantify the total impact of the Nuffield Council on Bioethics. Many of the strongest indicators of the Nuffield Council on Bioethics' impact are qualitative.

Several of the Nuffield Council on Bioethics reports are perceived to have made an impact several years after their publication. It is therefore difficult to conclude that recent reports that are perceived not to have had a significant impact, will not impact future policy. For example, several stakeholders comment that the 'Biological and health data' report has not made a major impact. However, many stakeholders consider biodata to be an area of growing interest, so the report may make a greater impact in the future.

International stakeholder: *"Measuring the direct impact is very difficult - this is something that all bioethics councils struggle with."*

- **Visibility**

The Nuffield Council on Bioethics impacts both policy defined in parliament and policy developed within specific government departments, such as the Department of Health. Whilst policy defined in parliament is in the eye of the media and general public, policy defined within department is much less visible to broader audiences. As such, most of the stakeholders interviewed perceive the Nuffield Council on Bioethics' report on '*Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review*' to have had a much greater policy impact than reports such as 'Public health: ethical issues'. However, this is largely due to the relative visibility of the policy the reports sought to impact. Any impact that the Nuffield Council on Bioethics makes on the private sector or NGOs is also difficult to identify.

- **Timing**

Stakeholders report significant variation in how much impact the Nuffield Council on Bioethics' reports have. The factors defining whether a Nuffield Council on Bioethics report makes an impact on policy or public debate are largely external. If a Nuffield Council on Bioethics report is published ahead of that topic becoming the focus of political and public attention, it is likely to make a much greater impact. '*The Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review*' is given as an example of this by many stakeholders.

Media: *"If [a Nuffield Council on Bioethics report] is not covered it's because the media are not interested, not because they haven't tried"*

Policymaker: *"Almost all reports are capable of making a policy impact"*

- **Process**

Whilst the trends in political and public debate are outside of the Nuffield Council on Bioethics' control, the organisation does have control of when reports are written and the length of the report development process. The Nuffield Council on Bioethics' academic rigorous report writing model prohibits the organisation from responding to bioethics questions that emerge unexpectedly into public and political debate. It is very difficult to predict important bioethical questions for the UK several years in advance.

Research funder: *"There is a tension between producing thoughtful, deep analysis and moving quickly to influence the debate"*

5.5 Stakeholders' future recommendations for the Nuffield Council on Bioethics

During the interviews, many stakeholders shared their views about what the Council should do in the future. Several survey respondents also left comments with future recommendations for the organisation. These can be grouped as follows:

Maintain ongoing role

Stakeholders agree there is an on-going role for the Nuffield Council on Bioethics in informing and influencing debate around bioethics. For the most part, stakeholders interviewed agreed that bioethics will remain a source of strong public, political and media interest over the coming years.

Learned society / Professional body: *"Policy makers have a great recognition of the evidence base offered by academics, but there is a need for organisations like the Nuffield Council on Bioethics to synthesise it... Recognition of evidence in policy making has never been as strong. It's the golden age for this."*

Greater engagement with audiences

Several stakeholders suggested that the Nuffield Council on Bioethics could have a stronger impact on its audiences by more active engagement and advocacy for the use of its reports. This would increase the attention that the Nuffield Council on Bioethics receive from those that it seeks to influence. Many other stakeholders question whether more direct lobbying would undermine the Nuffield Council on Bioethics' reputation for being independent and non-partisan.

Private sector: *"They have this very high quality work, which is just sitting there in the dark room"*

Topic selection

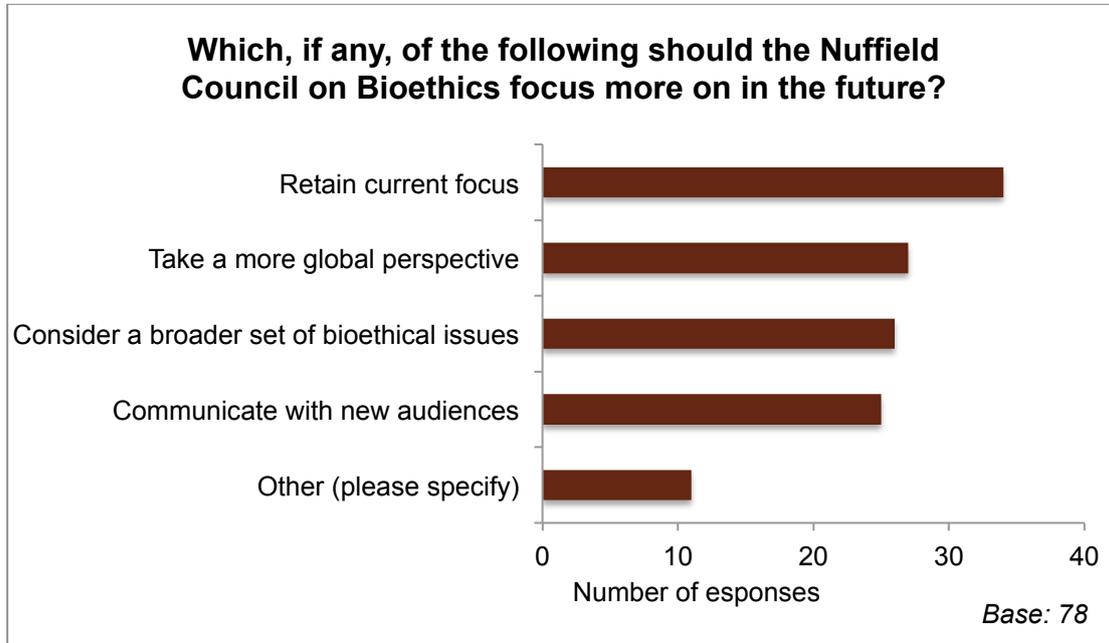
Very few stakeholders interviewed consider any topics to be 'missing' from the Council's portfolio of reports, but many stakeholders find the reasons for topic selection unclear. A small number of stakeholders report that the topic selection process has become more transparent in the last 5 years, but a clearer framework for prioritising topics may make the process even more transparent to stakeholders.

Most academic stakeholders interviewed see the Nuffield Council on Bioethics' topic selection process as academically thorough and almost all stakeholders perceive a diverse range of academic views to be considered in topic selection. However several non-academic stakeholders question whether the Nuffield Council on Bioethics should also consider the views of more non-academic experts in the forward look meetings.

5.6 Survey respondents future recommendations for the Nuffield Council on Bioethics

There was no clear consensus amongst the survey participants on the future priorities for the Nuffield Council on Bioethics.

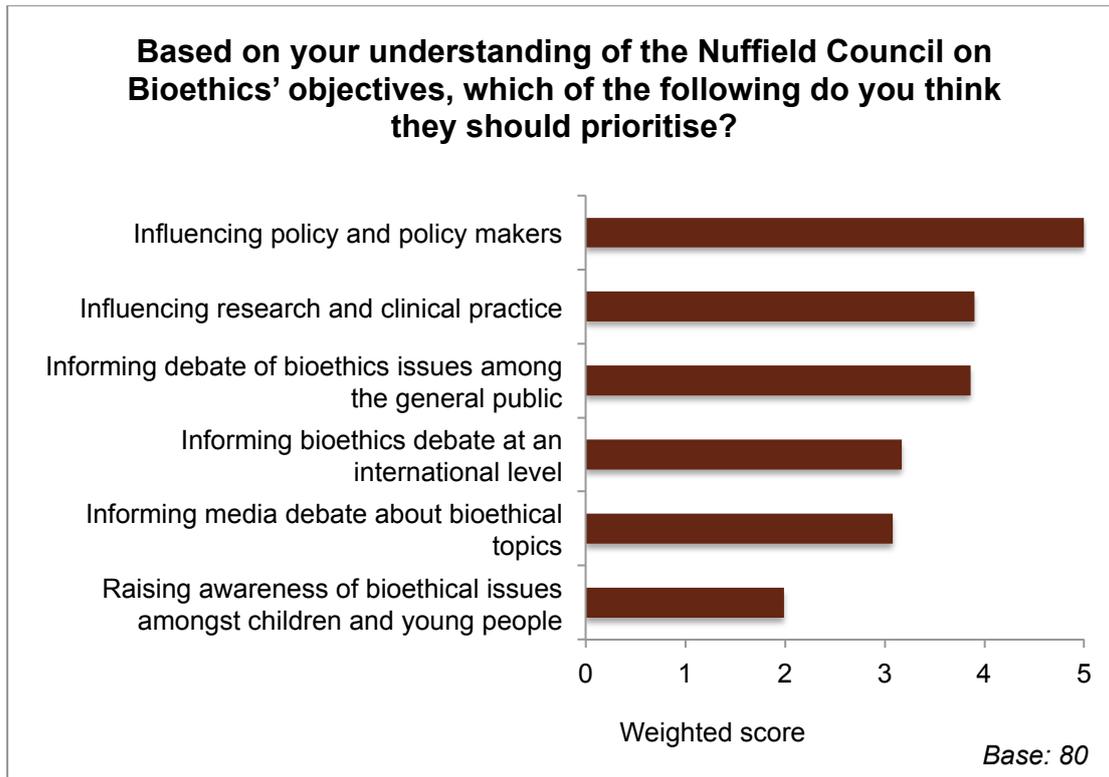
Figure 6: Survey respondents – future focus



44% of respondents think the Nuffield Council on Bioethics should retain its current focus. Similar numbers of stakeholders encourage the Nuffield Council on Bioethics to pursue one of the other options. The number of respondents who think the Nuffield Council on Bioethics should take a more global perspective is particularly high, given that 83% of participants are based in the UK.

Survey participants were asked to rank the statements below in terms of priority for the Nuffield Council on Bioethics.

Figure 7: Survey respondents – future priorities



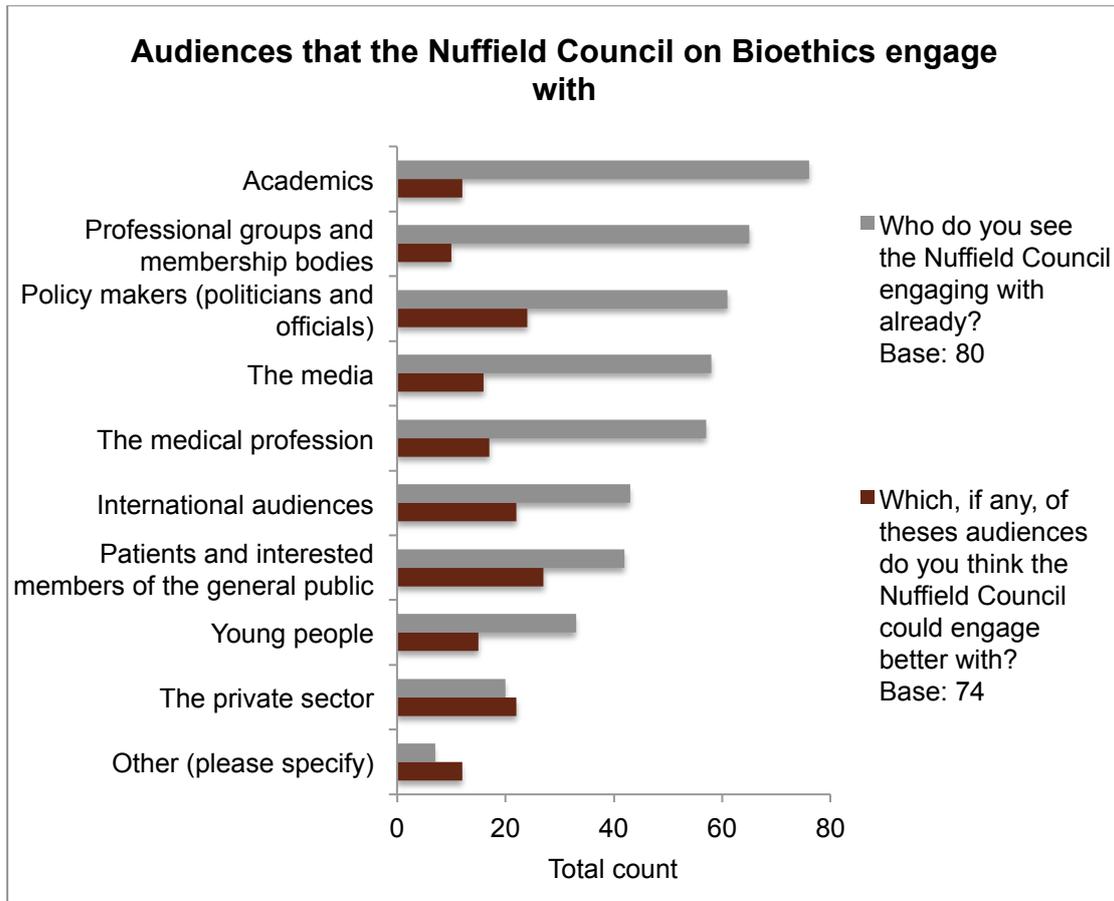
Influencing policy and policymakers, which is closest to the Council's original role, received the highest weighted score. This indicates that the Council's wider stakeholder groups still see this as the core of the organisation.

Respondents also ranked influencing research and clinical practice and informing debate of bioethics issues among the general public highly.

Informing bioethics debates at an international level and informing media debate about bioethical topics are seen as less important by the survey participants. This may be partly reflective of the primarily UK based and academic sample of respondents.

Respondents were also asked about the audiences that they see the Nuffield Council on Bioethics engaging with today and who the organisation could engage better with in the future.

Figure 8: Survey respondents - audiences



95% of respondents report that the Nuffield Council on Bioethics engages with academics, professional groups and membership bodies, policymakers and the media. Young people and the private sector are seen to have the least current engagement

Respondents identify opportunities for the Nuffield Council on Bioethics to engage better with patients and interested members of the general public, policymakers, international audiences and the private sector. Again, this reflects feedback from the qualitative interviews.

6 The Nuffield Council on Bioethics operating model

6.1 *The role of the Council's operating model*

A key requirement for this project was to evaluate the Council's progress against its strategy. Stakeholders' perceptions of progress against the objectives set out in the 2012-2016 strategy are assessed in section 4 of this report. However, in practice, the strategy document capturing those objectives is an incomplete baseline for considering the strategic direction of the organisation. Additionally, understanding of both the strategy and the Council's progress against it was low.

As an organisation, the Nuffield Council on Bioethics has many procedural guidelines but few strategic or operational plans. The 2012-2016 strategy document concentrates on values and ways of working rather than setting challenging goals for growth or change.

According to multiple stakeholders and our own analysis, the strategic objectives have not guided action and direction as much as the Council's core processes for generating reports and the operating model designed to support them. The strategic objectives are not well known to stakeholders, whereas the 'core process' is well understood.

In addition, many stakeholders felt that the process itself was a primary contributor to the organisation's impact. The rigour, integrity and inclusiveness with which the Council produces reports is central to the Council's reputation.

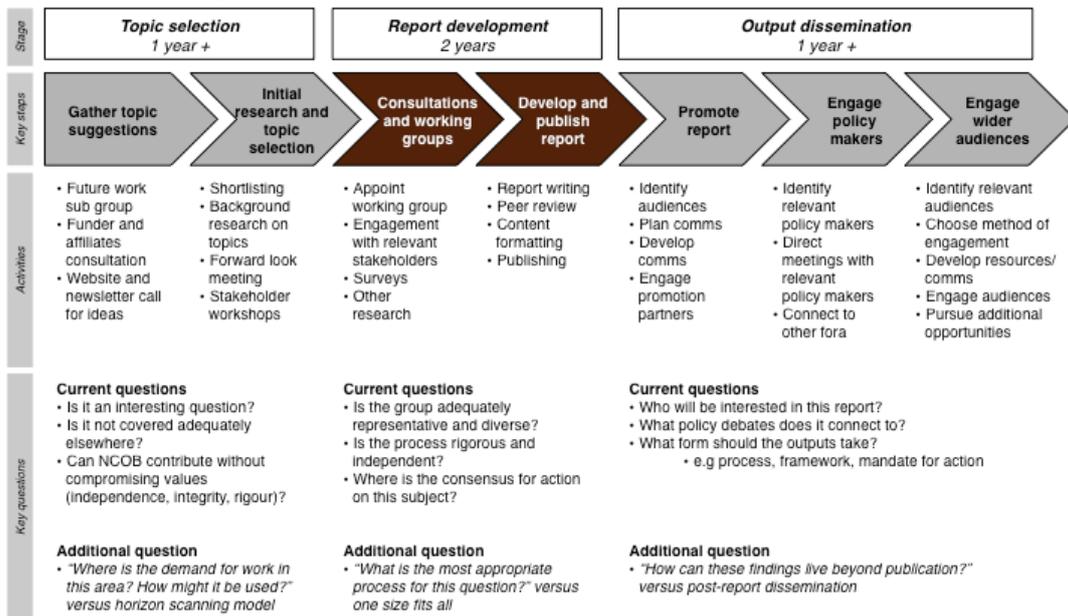
Academic: *"[The report development process] is the backbone of the Nuffield Council of Bioethics."*

Media: *"I am very critical of lots of organisations but I am not critical of them"*

However, a number noted that the approach is inflexible and potentially limits the Council's ability to respond to change, include new audiences or consider different ways of working. This section looks at how the current operating model works, the strengths arising from that model, the potential areas for development, and the consequences of changing the approach.

6.2 The current operating model

Figure 9: The Nuffield Council on Bioethics value chain



The Nuffield Council on Bioethics has a 'product' focussed operating model, built around producing its reports. This is shown by in the organisation's value chain above.

At a high-level, there are three key steps in the Council's process: i) Topic Selection ii) Report Development iii) Output Dissemination.

Whilst the timetable for each report differed, in general each step could take several months to two years.

6.3 Topic selection

The Nuffield Council on Bioethics Strategy document describes the criteria used to assess the potential suitability of a topic. Issues must:

- Be novel: be linked to substantial new developments in medicine or biology
- Raise ethical questions and concerns of some complexity
- Be timely: the Council aims to be proactive in its selection of new topics
- Lead to work that would be likely to have an important impact on policy or practice
- Be within the Council's terms of reference

These criteria ensure that potential topics meet a minimum level of suitability. Some marginal cases, such as health system resource allocation in the NHS and assisted dying had been considered at length at this stage, but rejected as candidates for new work. One reason for this was that additional informal criteria were used by stakeholders at this stage. These include a desire not to replicate work being done by other agencies (such as NICE) or to consider questions of such broad scope that they become political and social issues. For a number, this line in particular was blurring.

For some, many of the issues now arising in bioethics are about “rethinking old issues for a modern context”. The need to consider the broader social and political aspects of a question make bioethical issues more complex, abstract and systemic. This leads to more abstract terms of reference, which makes it harder to scope out a clear question for investigation.

Academic: *“We think we’re working on ethics, but really we’re working on politics....It’s becoming harder and harder to find a Nuffield-style question.”*

Whilst understanding of the topic selection process was mixed, most stakeholders felt that the process was robust and that few topics had been ‘missed’ by the Council. A number of stakeholders had participated in forward look meetings, and felt that the calibre of the people involved gave them confidence that the ‘right’ topics were under consideration.

The question that is not explicitly asked at this stage is who the audience for this work is and how it will be ‘consumed’. Whilst the Council has a good record at making an impact with policymakers at salient moments, the length and formality of the process meant that it does not respond quickly and typically only uses one model for engaging with issues.

A number of stakeholders commented that this process looks only at topics, and not the way in which the Council might tackle a topic. The suggestion was that there could be an associated process, (or a stage in topic selection) that considers different ways of approaching programme design, audiences and methodology for the reports.

6.4 Report process

As noted in the section on impact, the rigour and integrity of the process of developing reports is one of the main contributors to the Council’s reputation.

For some, the process itself was the most important output of the Council, and the basis of the organisation’s mandate and authority. One academic stakeholder described the role of the Council as an ‘enterprise in public rationality’:

Academic: *“The most interesting questions are where sensible people disagree. So the challenge is to work in those areas of multiple strongly held views and get to some sort of closure. [The Council] does this by building common ground, establishing the legitimacy to move forward and creating an environment in which decisions can be made. It’s about establishing the ground rules for public debate.”*

The strengths of the report writing process are outlined in the impact section. The main criticisms of the current process were that it was inflexible, slow and ‘one-size-fits-all’.

Some felt that the gaps between launches, working groups and publications were too long and that issues demanded quicker responses.

A number of stakeholders suggested that there was an opportunity to consider alternative ‘products’ or ways of working.

One stakeholder suggested that the report on ‘*Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review*’ was the Council’s first attempt at a ‘quicker’ piece of work and that it provided a potential model for the future.

However, if alternative models were more explicitly pursued, either for new audiences or different ways of responding quickly to new issues, the Council would have to consider how to protect the integrity of its 'gold standard' reports generated by its core process.

Private Sector: *"I'd love to see [the Council] sitting down with the Academy of Medical Sciences, with the MRC, the ESRC and bringing groups together. It doesn't always have to provide a report each time. It should be working with other bodies, stimulating debate. More half-day activities, lectures, bring over US, European, Chinese experts and share perspectives from around the world."*

6.5 Output dissemination

The process of dissemination was described by one stakeholder as the period of "post-report diplomacy". In general, demand for engagement after a report launch was thought to be growing, increasing the pressure on senior leadership to participate in policy debates.

Understanding of the role the Council does and should play in the dissemination of its reports was not high among stakeholders. Some suggested the current approach was effective, whilst others suggested the Council should participate in public debates as a media commentator shaping public discourse.

One major issue is that the 'report launch' phase was a distinct period of time, and the opportunities to engage with key audiences pre- and post- launch were limited by this way of working.

The Nuffield Council on Bioethics struggles to engage with audiences and stakeholders outside of the roles that are typically required by the report and dissemination process described in the picture above. A small number of stakeholders mentioned specific examples of when the Nuffield Council on Bioethics were unable to work in partnership outside of this process.

6.6 Limits of the current operating model

At a high level, the Council's process shares many characteristics with a traditional academic publisher. They receive submissions, develop publications, and distribute them.

There are significant differences. The Council has convening power, transparency, a collaborative approach and a different funding model. However, many of the challenges faced by academic publishers are shared by the Council:

- The changing audiences for their work mean that there is an opportunity to think beyond traditional stakeholders in academia and policy, to influencers in other sectors and institutions.
- New collaborative technologies create new opportunities for more "open" processes, which can increase diversity, build new mandates as well as create fundamentally different ways of working.
- An operating model dominated by a publishing cycle means that it is hard to establish a persistent role in relevant debates. A couple of stakeholders mentioned occasions where an issue had risen to public or political prominence and the Council had not

responded to it “because they had already done something on that”. An operating model less governed by a publishing cycle could be more flexible.

- Academics are increasingly encouraged to think about their impact beyond journal citations, creating a challenge to the journal as a repository of academic reputation.

In general, these trends mean academic publishers will have to become more outward-looking, more responsive to their audience, more collaborative, rethink their ways of working and their funding models. Many of these challenges hold true for the Council. The challenge is to respond to these trends without undermining what makes the Council’s work valuable in the first place.

6.7 Funding model

The Nuffield Council on Bioethics is unlike most other national bioethics councils in that it is a non-statutory body receiving grant funding from a mix of philanthropic and research funders. It is unlike many charitable entities in that its funding is largely unrestricted. It is also not a legally constituted entity.

Policy maker: *“[Nuffield Council on Bioethics have a challenge to avoid] being taken for granted, particularly by funders. They have got to emphasise their value. If they didn’t exist we would be in a worse place”*

Most of the Nuffield Council on Bioethics’ stakeholders are aware of the organisation’s three funders and many feel these are the natural funders for the organisation’s work. Some commented that the Wellcome Trust and MRC were the primary users of the Council’s outputs. If they did not fund the work of the Council, they would have to do similar work themselves in-house. One private sector stakeholder suggested the Nuffield Foundation was more ‘hands-off’ by comparison.

Many stakeholders see the funding model as an important part of the Nuffield Council on Bioethics’ independence, though recognise that this comes with increased financial uncertainty. The Council is given a high degree of independence by its funders. All of the core funding is unrestricted and the funders do not dictate the topics that the Council work on. There is a very small amount of funding from other sources for specific programmes. The Council’s growing international role and broader public engagement has to be funded by the fixed core funding budget.

The input of leading academics is crucial and key to the Council’s success, though most of this is voluntary. We have modelled the total value of the academics’ voluntary contributions and estimate that the Nuffield Council on Bioethics unlocks contributions worth an additional £245,000 per year.

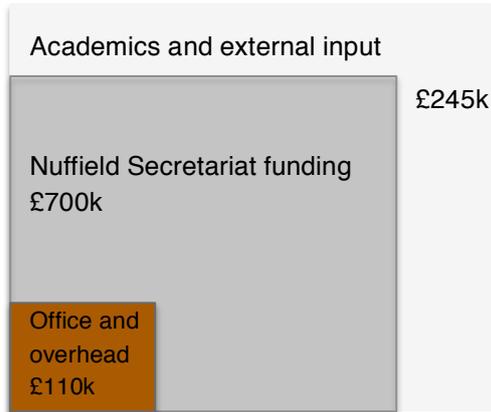
Most of this contribution comes from Council members and Working Party members that contribute to Nuffield Council on Bioethics meetings and reports.

A smaller amount of this value is leveraged by members of other committees, such as the Educational Advisory Group meetings, Council subgroup meetings and Forward Look meetings.

In order to build a full picture of the Council's financial framework, we have also included another £110k of office and overhead costs. These services are donated in-kind by the Nuffield Foundation.

In 2013, the Nuffield Council on Bioethics received a total of £758k in funding. Based on our model, we estimate that for each £1 of core funding, the Nuffield Council on Bioethics unlocks a further 32p.

Figure 9: Total leveraged costs - £245k



7 Considerations for the future

As the Council looks to the next five years, this evaluation identifies three questions to answer:

- How does the Council preserve the core of its work, ensuring that the future strategy does not undermine the Council's excellent reputation?
- How does the Council develop, implement and monitor strategy?
- How should the Council think about changes in its audiences, operating model, funding structure, and international role?

7.1 *Preserve the core*

The Nuffield Council on Bioethics is highly regarded, and is seen as a reputable body playing an important role in the UK's policy landscape. Much of this reputation is attributable to its processes and people.

As the Council moves into a new funding period and is tasked with developing a strategic plan for the next five years, it will need to consider its response to a number of the issues raised in this evaluation, such as how it engages audiences, new operating models, new funding structures and international role.

In addition, more internally-focussed issues, such as governance and the capabilities of the Council, should also be considered by the new strategy, though it is beyond the ability of this review to comment in detail upon them.

In considering all of these questions, the Council should consider the potential impact on its reputation as an institution and the integrity of its current process and current outputs. These should be protected under all circumstances.

A more flexible, more audience-focussed approach could increase the reach, impact and relevance of the Council. However, if these new approaches are executed poorly, they could undermine the reputation for rigour of its core work and cause harm in the medium term.

7.2 *Strategy development*

Whilst the Council has a strategic plan, including a number of strategic objectives, it has not followed a clear 'strategy' that has driven action towards a defined set of outcomes.

The strategic objectives outlined in the strategy were not accompanied by a clear plan of how they would be achieved, nor has progress against them been regularly tracked and monitored.

The most significant issues – the topics to work on, the nature and composition of the working groups, the audiences to be engaged - are accommodated by the core process. Success in these areas is outside the scope of the current strategy.

Many of the issues raised in the plan, such as "diversity" and "quality" were loosely defined and not measured or reported.

The initiatives and objectives outlined in the strategic plan gave rise to a number of new projects (such as the affiliates database) and Council subgroups immediately after the report launch, but the day-to-day salience of the strategy appears to have been low.

Other significant strategic considerations not included in the strategy, such as thinking about international engagement have been tackled in a more ad hoc and organic way by the leadership team.

There has not been a proactive strategy to consider and manage change, based on a clear understanding of how the world is changing and the Council's emerging role in that world. The strategy does not have a clear definition of success, and it is difficult to meaningfully measure progress against it.

In this next funding period, the Council should consider a strategic planning process that more deliberately considers:

- **Outcomes:** The strategy should establish clearly the outcomes the Council is working towards in support of its mission based on its understanding of its role in the world. These outcomes should have a clear definition of success.
- **Implementation:** The strategy should describe a clear plan for achieving these outcomes, allocating resources to them and ensuring it has the right capabilities.
- **Evaluation:** For this next strategy, the Council should more explicitly monitor its progress and iterate plans over time.

In developing and reporting its strategy, the Nuffield Council on Bioethics could think more broadly about its impact, and how that impact is manifested, captured and evaluated. The stakeholders engaged during this process tell a much stronger story of impact than is currently captured by the Council's reporting. This review established that the work of the Council has impact in terms of establishing frameworks for policy discussion, shaping private sector behaviour, directly influencing legislation and other outcomes.

At present, the Nuffield Council on Bioethics mostly tracks references to the Council's reports by relevant bodies, as well as references and citations of the reports in other articles or books. This type of measurement is needed for academic institutions who are required to adhere to the REF and other traditional measures, but the Nuffield Council on Bioethics is not constrained by this framework. The direct impact on specific policies could be highlighted more clearly. Broader measures, such changes in attitudes amongst particular audiences, could also be considered.

Policy maker: *"They do need to demonstrate impact and can't live in an ivory tower"*

7.3 New issues

The new strategy will need to address questions around the following issues:

- Audiences and communications
- Operating model
- International role
- Funding model

These questions arise largely in response to issues raised by stakeholders critiquing the current approach, identifying opportunities for increased impact and anticipating areas of increased demand.

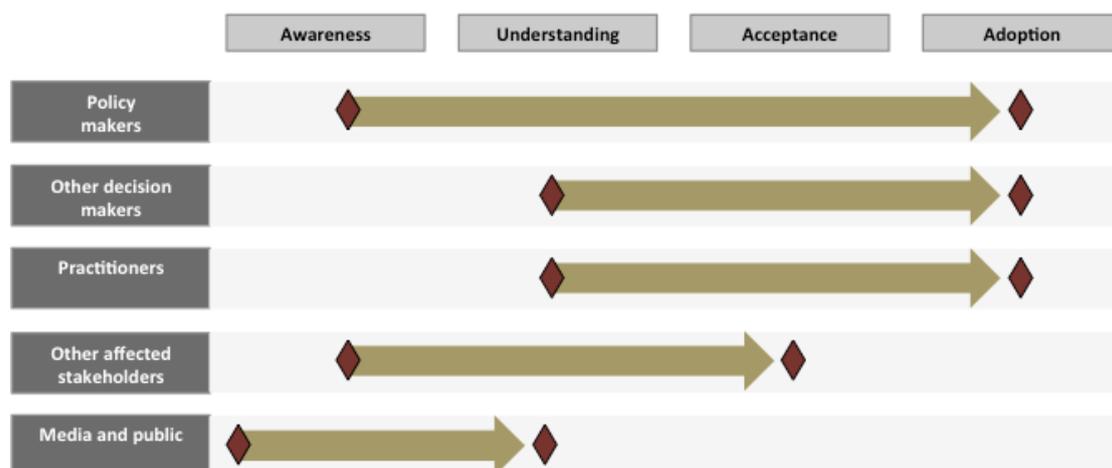
Audiences and Communications

The Council could take a more deliberate approach to thinking about its audiences, the change it wants to see and the conversation it wants different audiences to participate in. At present, communications activities are concentrated in post-report launches and senior engagement with decision-makers in the post-report period. Periods of high political interest also create demand for communications and engagement.

Audiences can be thought of in a number of simple groups: as policy makers, other decision makers, practitioners, other stakeholders (for example, patients), the media and public.

To engage with these groups effectively requires a more explicit communications and engagement strategy, with clear outcomes and objectives. A simple model for this is shown below.

Figure 11: Illustrative audience strategy



This illustrative example maps current and desired positions for some of the Nuffield Council on Bioethics' audiences. The desired position for each audience gives an indication of the type of engagement needed to influence them successfully. The Council not only needs to

establish where audiences are today and what it is trying to achieve from its engagement, but how in practice it might achieve that change. This could result in lots of new activity.

For some, the Council is primarily a crucible of expert academic opinion, the primary audiences are academics and policymakers and the current approach to communications is adequate. For others the Council needs to be more inclusive of other expert, practitioner, and beneficiary voices, and work towards building a broader public mandate. These more clearly demand changes to the Council's approach to engagement. However, it may be more effective to introduce changes that make the Council's operating model more flexible and inclusive (see below) than by becoming a media commentator on bioethical issues of public interest.

Operating model

As discussed earlier in this report, the Nuffield Council on Bioethics' current operating model is focussed around producing reports as individual 'products'. Whilst academically thorough, this process received some criticism for being too slow, inflexible and unresponsive.

The Council could consider a number of ways to address these issues:

- **Move from 'producing reports' to 'managing programmes'**

The Council could move from an approach based on 'producing reports' to a series of ongoing programmes. These programmes (covering specific topic categories) could allow for a more 'modular' approach rather than the current, consecutive steps of the report development process. Communications and engagement around programmes would be ongoing, rather than pre- and post- report launch. A programme approach would be more responsive to the needs of policymakers and other audiences. Individual programme elements could attract specific funding. It could also bring additional structure to the topic selection process. This would allow greater flexibility of approach, a broader, more diverse conversation and a different type of public mandate.

- **Combine 'topic selection' with choices about 'programme approach'**

Another way to introduce flexibility into the process is to consider which methodological approach is most appropriate for each issue. At present, there is a perception of a 'one-size-fits-all' methodology. In the future, the Council could choose to tackle large, abstract social/political issues in one way, high profile policy questions in another, and so on. The choice of approach would be driven by consideration of context, timing, resources and impact.

- **Produce short reports to respond quickly to emerging issues**

Interviews suggest that some bioethics topics emerge and very quickly become prevalent in political and public debate. The Nuffield Council on Bioethics' standard approach does not allow full reports to be developed in these cases. The Council could consider producing 'light' reports in these cases. The thorough report development process is at the heart of the Nuffield Council on Bioethics' credibility, so any 'light' reports would need to be clearly labelled, branded and communicated as a distinct.

International role

Today, most bioethics councils have a national focus, but many stakeholders foresee a more global role for bioethics. Interviews show that the Council's work has already made an impact at an international level. There is in a sense that demand to engage with international audiences, collaborate internationally, participate in international fora and support the development of bioethics groups in other countries will increase. This will create additional pressure on resources, especially senior leadership. In addition, the Council could proactively choose to conduct more projects with more explicitly 'international' terms of reference.

These activities are on the fringes of the Council's current terms of reference, priorities and funding. If there are to become more central to the Council's work, it will require clear definition of audiences and will likely require separate additional funding and resources. The Council will also need a framework for deciding which of these activities to prioritise.

Funding

Most stakeholders interviewed considered the Council to be an important and essential part of the UK policy landscape.

Under the current funding structure and operating model, it was not thought appropriate by many for the Council to accept funds from private sector donors. The requirement for countries to have a national bioethics council suggested that in a worst case scenario there would likely be some government funds available, but this would not necessarily go to the Nuffield Council on Bioethics, nor replicate its current role.

Under a more programme-based model, and with investment in fundraising capacity, it may be possible to raise specific project funds from donors and to manage the reputational risk, but these funds would only ever be complements to core funding. It is not clear who, beyond the current funders, is likely to offer core funding at current levels.

Any significant change in funding levels or funding agencies may well result in more fundamental changes to the Council's operation, form and position in the UK policy framework.

Funders were not interviewed for this evaluation, so their perspective on future funding is unknown.

8 Appendices

Appendix 1

Draft external stakeholder discussion guide

This document outlines suggested themes for the stakeholder interviews. We will tailor questions for specific groups/audiences depending on individual interviewees' role/sector and relationship with your organisation.

Introduction

- Thank respondent for their involvement. Confirm purpose of discussion and explain the process including Firetail's role as independent evaluators
- Assure of confidentiality (comments will not be attributed to individual stakeholders unless they request this). Seek permission to record discussion (again, assuring anonymity and that recordings will only be used by Firetail for reporting purposes)
- Confirm that the evaluation will not be made available in the public domain
- Interviewee and interviewer to introduce themselves

Relationship with and understanding of the Nuffield Council on Bioethics

- How did you first come into contact with the Nuffield Council on Bioethics?
- How do you engage with the Nuffield Council on Bioethics? (Affiliate, previous committee member, contributor to consultations or meetings, user of resources etc.)
- What do you understand the Nuffield Council on Bioethics' mission and objectives to be?
- To what extent do you support its mission and objectives?
- What do you understand the Nuffield Council on Bioethics' current strategy to be? (prompt on whether they have seen the 2012-2016 document)
- Who is the Council's work aimed at?
- Who *should* our work be aimed at? Why? (policy makers, clinicians, researchers, industry, patients, young people, the media, general public)
- To what extent do you feel the Nuffield Council on Bioethics writes its reports and other documents for a specific audience/s?

Perceptions of the Nuffield Council on Bioethics' work

- How effectively do you feel the Nuffield Council on Bioethics is working towards its objectives (i.e. those you identify)?
- Can you provide examples of where the Nuffield Council on Bioethics has been effective in this respect?
- Can you provide examples of where it could be more effective?
- Do you have any other feedback on the Nuffield Council on Bioethics' strengths and weaknesses?
- *(If not already mentioned, and selecting questions appropriate for the interviewee)*
How do you rate the Nuffield Council on Bioethics' effectiveness in terms of:
 - Diversity of input into its work (prompt on type of diversity, opinions or people)
 - Identifying and reaching its audiences

1. Policy makers (e.g. government, parliament, regulatory bodies)
 2. Other relevant decision makers (e.g. professional bodies, senior researchers)
 3. Practitioners (e.g. healthcare professionals, scientists, other researchers, funding bodies)
 4. Relevant affected stakeholders (e.g. patients, families)
 5. Interested members of the general public
 6. International audiences
- Identifying and engaging appropriate partners (Probe for effective engagement with interviewee, policy makers, contributors to papers, relevant media partners and new audiences)
 - Range of activities (e.g. writing and publishing reports, putting on events, education, engaging relevant audiences)
 - Relevance and appropriateness of the selected topics (has it missed any topics?)
 - Collaborating with other organisations
 - Quality of its published reports and other resources
 - Communications tools and approach
 - Collaborating with other organisations

(For close stakeholders only)

- Transparency (prompt on activities, plans, policies/procedures, findings/data, finances)
- Diversity and number of Council members
- Monitoring and evaluation of quality, reach and impact
- Reporting and governance
- Business planning
- Flexibility in ways of working
- Topic selection process

Use and impact of the Nuffield Council on Bioethics

- How would you describe the wider impact of the Nuffield Council on Bioethics, to date?
- Where, if anywhere, do you see its influence?
- To what extent does the Nuffield Council on Bioethics influence policy in the UK? (prompt on the influence of the organisation and the influence of its work)
- Have you seen/heard evidence of the Nuffield Council on Bioethics' work being referenced? Resources used? Which? Where? Who is using them? To what effect?
- Have you ever looked for specific work by the Nuffield Council on Bioethics and found that it has not been done, or what had been done was not helpful?
- To what extent is the Nuffield Council on Bioethics a recognised voice on bioethics, nationally and/or internationally?
- What are its main routes to influencing policy?
- To what extent does the Nuffield Council on Bioethics or its work influence other bioethical decision making groups? (e.g. clinicians, researchers)
- To what extent have you used the Nuffield Council on Bioethics' resources? (probe for any specific resources, how these have been used, with which audiences and to what effect)
- Can you think of any examples where the Nuffield Council on Bioethics' work has made a difference to you/the organisation you represent/your sector?

- Have you communicated the work of the Nuffield Council on Bioethics within your organisation? And outside your organisation? Have any of the Nuffield Council on Bioethics resources been disseminated/referred to in this context?
- How effective is the way in which the Nuffield Council on Bioethics shares its resources?

Landscape

- How would you describe the landscape in which the Nuffield Council on Bioethics is operating?
- Who are the main actors in bioethics in the UK? (prompt on how the groups of actors are changing and any new actors emerging)
- Where does Nuffield Council on Bioethics sit in relation to others in this space? What is its scope of work? (prompt on comparative strengths and weaknesses)
- Is bioethics a growing or decreasing challenge in the UK?
- Who are the Nuffield Council on Bioethics' closest international peers? How does the Nuffield Council on Bioethics compare to them?
- What does the bioethics landscape look like outside of the UK? Where does Nuffield Council on Bioethics sit in relation to others in this landscape?
- To what extent do you expect the bioethics landscape to change? In the short term, i.e. the next 2 years. And in the medium term i.e. in 2-5 years? (probe for reasons for change, new actors etc.)
- What do you see as the main sources of funding for bioethics? How is this changing? (prompt on new or growing sources of funding)
- Which areas of bioethics attract the most funding?
- How would you describe the relationship between academics and policy makers? How is this changing?
- How would you like the Nuffield Council on Bioethics to respond to this changing environment? What opportunities and threats does it present?

The Nuffield Council on Bioethics and the Future

- Looking ahead, what opportunities are there for the Nuffield Council on Bioethics? (prompt on audiences, activities and funding)
- Looking ahead, what challenges does the Nuffield Council on Bioethics face?
- What do you anticipate will happen to its level of reach/impact? What factors will determine its success in this respect?
- If you were starting from scratch, how would you set up the Nuffield Council on Bioethics or do things differently?
- Do you have any other advice for how the Nuffield Council on Bioethics could be more effective?
- Final comments

Close interview and thank interviewee. Explain next steps

Appendix 2

Brief for engagement, evaluation, and strategic activities to inform Nuffield Council on Bioethics funding proposal 2017-2021

February 2015

Since the early 1990s, the Nuffield Council on Bioethics has been funded by the Nuffield Foundation, Wellcome Trust and Medical Research Council on a succession of five-year grants. As it approaches the end of its current funding period (2012-2016), the Council is preparing to develop a proposal for funding for the period 2017-2021, which will be submitted to its funders at the end of November 2015. The Council will be carrying out activities internally to inform the proposal, including conducting a review of the impact of the Council's work on public discussion and policy, and holding a workshop for Council members and staff to deliberate future objectives and operating procedures. The Council is also looking to employ consultancy services to carry out a number of other activities to inform the development of the proposal. It is anticipated that these will consist of two contracts, which could be awarded separately or as part of a package to a single consultancy. The activities to be carried out externally are:

- 1 **Stakeholder engagement** – gathering the views of our stakeholders on whether we have achieved our objectives as set out in our [Terms of Reference](#), and what we should be aiming to achieve and how we should do things in future.

Budget: approximately £15,000.

2 Strategic Planning

- a. Evaluation of implementation of [Strategic Plan 2012-2016](#) – review of whether and how the Council has met the commitments set out in its Strategic Plan, including procedures for topic selection, work planning and outputs, management, governance and evaluation.
- b. Input into draft Strategic Plan 2017-2021– input into the development of a Strategic Plan for the next funding period.

Budget: approximately £10,000.

Details

1 Stakeholder engagement

We are looking to work with a consultancy to develop a programme of stakeholder engagement activities in order to gather evidence on a) whether our stakeholders believe we have achieved our objectives as set out in our [Terms of Reference](#), and b) their views on what we should be aiming to achieve and how we should do things in future.

We would like the consultancy to help identify which stakeholders we should engage with during in this exercise. There is a wide range of organisations and individuals who are interested in bioethics and who often contribute to and use the work of the Council. Additionally, each of the Council's projects has its own specific set of stakeholders dictated by the topic being considered. Our stakeholders include (particularly in the UK, but also Europe and worldwide):

- Government departments and bodies, including the NHS
- Parliamentarians and parliamentary committees
- Learned societies and professional bodies
- Academic institutes and researchers
- Journalists
- Pharmaceutical and biotechnology companies
- Organisations involved in school and informal education
- NGOs, charities and campaigning organisations

We would also like the consultancy to propose a set of activities that would best engage the identified stakeholders within the budget and time available. Activities might include an online survey, group meetings and/or individual interviews. The consultancy should also help develop the specific questions and topics to be discussed during the engagement activities to enable us to gather the evidence we need.

The consultancy should carry out the stakeholder engagement exercise and deliver a final report of the findings by the **end of May 2015**.

2 Strategic Planning

a. Evaluation of implementation of Strategic Plan 2012-2016

As part of the last funding proposal, the Council published a [Strategic Plan 2012-2016](#). In the plan, the Council said it would ensure that:

- It has a diversity of input into its work, ensuring that as wide a range of people as possible are able to contribute.

- It has a wide reach so that both the policy impact and the promotion of public debate are maximised.
- It maintains a range of activities so as to better inform and engage a wide range of audiences.
- It is as transparent as possible so that it is clear to stakeholders how the Council operates and how to interact with it.
- It has appropriate ways of evaluating its own quality, reach and impact.
- It has reporting and governance arrangements in place that support these aims.

Further details are set out in the Strategic Plan.

We would like to commission an independent evaluation of the extent to which the Council has met the commitments set out in our Strategic Plan. The evaluator would be invited to meet and discuss the work of the Council with its Chair and members, and with key staff. All relevant documentation would also be made available, such as:

- Council meeting agendas, papers and minutes
- Progress reports produced for the Council's funders
- Annual reports and accounts
- 'Impact statements' on the impact and reach of the Council's reports
- Standard Operating Procedures manual
- Recent publications including reports, consultation documents, education materials and website copy.

A final report of the findings of the evaluation should be delivered by the ***end of May 2015***.

b. Input into draft Strategic Plan 2017-2021

The Council will be drawing on the findings of all the activities carried out for the funding proposal in order to develop a Strategic Plan for the period 2017-2021. A draft of the Strategic Plan will be included in the funding proposal (to be submitted at the end of November 2015), and finalised in 2016. Although the Council will be taking the lead in the development of the Strategic Plan, we would like to obtain the advice of independent experts during the process.

The Strategic Plan will be developed and finalised ***between June and October 2015***.