Media coverage of the ethical and social implications of human genetic research

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Other related outputs:

Haran, J Kitzinger, J, McNeil, M O'Riordan, K (2008) *Human Cloning in the media: from science fiction to science practice.* Routledge, London

Henderson, L and Kitzinger, J (2007) "Orchestrating a science 'event': The case of the human genome project" *New Genetics and Society*. 26(1).

Kitzinger, J (2006) Constructing and deconstructing the 'gay gene': media reporting of genetics, sexual diversity and 'deviance' In Ellison, George and Goodman, Alan (eds) The Nature of Difference: science, society and human biology'. Taylor and Francis. pp, 99-117.

Kitzinger, J (2006) 'The role of the media in public engagement with science in Turney, J (ed) Engaging Science: thoughts, deeds, analysis and action. Wellcome Trust.

Kitzinger, J & Reilly, J (1997) 'The rise and fall of risk reporting' *The European Journal of Communication* 12(3): 319-350 (addresses journalistic practices, media reporting of human genetic research and early lack of attention to 'risk')

Henderson, L and Kitzinger, J (1999) The human drama of genetics: 'hard' and 'soft' media representations of inherited breast cancer' in *Sociology of Health and Illness, 21(5): 560-578* also reprinted in *Gabe*, J. and Conrad, P (eds.) *Sociological Perspectives on the New Genetics.* Oxford: Blackwells

Kitzinger, J and Davison, C (2001) *Public perceptions of social and ethical issues around GM foods: a focus group study*. Final report for the Wellcome Trust. Contact: kitzingerj@cardiff.ac.uk

Smart, A (2003) 'Reporting the dawn of the post-genomic era: who wants to live forever? In *Sociology of Health and Illness* 25(1): 24-49

Williams, C, Kitzinger J and Henderson, L (2003) Envisaging the embryo in stem cell research: discursive strategies and media reporting of the ethical debates *Sociology of Health and Illness, 25(7): 793-814*

Kitzinger, J and Williams, C (2005) Forecasting Science futures: legitimising hope and calming fears in the stem cell debate, *Social Science and Medicine 61(3):* 731-740

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1. Background and aims

Dramatic developments in human genetics offer great promise but also raise new questions about ethics, deployment of information, public involvement, and policy (BMA, 1992; Nuffield Council on Bioethics, 1993; Wilkie, 1993; House of Commons STC, 1995; Macintyre, 1995, 1996). It is the media which represent such debates to the general public and, as Wellcome states: 'Informed decision making, engaging the general public in constructive debate, is vital in a healthy democratic society' ('Helping Medical Science to Flourish' leaflet).

The media operate at the interface between science/scientists, and the social sphere/publics. They are thus a key site for exploring cultural images of science and its possibilities (Petersen, 2001) as well as being a crucial source of public information about medial research and policy (Miller et al., 1998). They are also an arena through which battles are fought and are often the focus of intense lobbying by competing sources (Philo, 1999). There is no necessary correlation between public 'opinion', public discourse and public policy (Condit, 1999). However, the media do have a strong influence on what, and how, things come to be defined as public issues. The patterns or coverage, the 'framing' of stories, the selective presentation of particular themes, 'facts' and claims rather than others, is a critical part of this (Hansen 2000; Petersen 2001). Research into how the media represent human genetic research is thus a vital part of any agenda concerned with the social aspects of science, including its public acceptability and the extent to which the public feel involved in, or are willing to challenge, scientific developments.

This project was designed to explore the ways in which ethical, legal and social issues [ELSIs] around new human genetic research [HGR] were represented in the media. We examined:

- the extent and nature of media coverage of ELSIs around human genetic research during a particular year (the year 2000);
- the ways in which coverage of HGR rose and fell during the year 2000 and how ELSIs were covered within this;
- the commonalities and differences between coverage in diverse outlets (press, TV, magazines), between different journalists (e.g. specialist or non specialist) and in diverse formats (including fictional representations, documentaries and chat shows);
- how journalists engaged with a specific news event - and the role of source organisations and individuals (e.g. scientists and press officers) in making an 'event' into a 'story';
- how the coverage of HGR and its associated ELSIs during the year 2000 compared to coverage during the preceding few years.

2. Methods

2.1. Data sets and sampling method

In order to examine these questions we compiled six main sets of material:
(a) A comprehensive archive of all national UK press coverage for 2000.
(b) A comprehensive archive of all main evening television news bulletins about HGR during 2000.
(c) A comprehensive archive of all non-news TV output e.g. documentaries and fiction about HGR during 2000.
(d) A sample of other types of media output during 2000: cinema releases, radio and magazines.
(e) Interviews with scientists, press officers and journalists involved in one major story from the year 2000 - the Human Genome Project announcement about completing the 'first draft' (June 2000)
(f) A retrospective sample of six newspapers for the years 1997-1999 in order to provide a recent historical/time perspective.

The method used for each area of data collection is detailed below.

(a) Monitoring the newspaper coverage in 2000
We collected all coverage of new human genetic research (HGR) for the year 2000 from all UK national newspapers. The national UK daily papers are *The Times*; *Guardian; Financial Times; Independent; Daily Telegraph; Daily Mail; Daily Express; Mirror; Sun* and the *Daily Star*. The national UK Sunday papers are the *Observer; Sunday Times; Independent On Sunday; Sunday Telegraph; Mail On Sunday; Sunday Express; Sunday Mirror; News of the World,* and *Sunday People.*

Hard copies of each newspaper were scanned manually every day. This involved skimming through a total of 3,120 daily papers and 468 Sunday editions i.e. 3,588 editions. The criteria for deciding that an item was 'about' HGR was whether it was mentioned in the title or first paragraph of the article and then discussed in the body of the text. We thus collected items about a wide range of issues to do with HGR (not just scientific reports about the research itself). The archive includes reports on the discovery of genes, the development of new medical applications, cloning, new reproductive genetics and discussions of insurance, patenting and other social and ethical as well as financial implications. We excluded items about animal genetic research unless they clearly referenced human applications (e.g. substantial speculation about how animal cloning could lead to human cloning).

The above data collection method identified 984 newspaper items (news reports, feature articles, editorials, columns, etc.) about HGR in the year 2000.[1]

(b) Monitoring the TV news coverage in 2000
In addition to the above we examined the main evening news bulletins on each of the five terrestrial channels. This involved BBC1 9 o' clock news; BBC2 *Newsnight*; ITN News at Ten/Nightly News, the Channel Four seven o'clock News and the Channel Five News at five thirty p.m. We also included the ten p.m. Sky Television news bulletins.

In order to identify all bulletins about HGR we started by obtaining listings from the TV companies and/or conducting our own electronic searches of their data bases. The search terms we used included: gene, genetics, clones, cloning, Human Genome Project and 'designer babies' (adapted where necessary to the search terms and criteria used by each data base). The list of bulletins generated in this way were then read in order to check that each item conformed to our inclusion criteria (as above) and any irrelevant items were excluded (e.g. those which were solely about animal genetics). These listings were then cross-checked with our newspaper listings for the year 2000 against all those dates when genetics made front-page news. The dates identified were amalgamated and all main evening news bulletins were then viewed for all those dates for relevant stories. (For example if a story was identified on BBC1 at 1 p.m. then the evening news was checked for that date also). In order to double-check this process a number of bulletins were cross-checked on days when particularly high-profile events took place. (This allowed us to confirm the comprehensive nature of our archive and also to identify how a story became 'knocked off' the agenda e.g. due to a breaking story in the Middle East).

The above data collection method identified 44 main evening news bulletins about HGR in the year 2000.

(c) Monitoring non-news TV output in 2000
Other TV output (documentaries, drama etc.) about HGR was identified by scanning the *TV Times* listings. If there was any suggestion that the programme might address relevant issues then it was taped and then watched. In addition we recorded a several whole series of medical dramas and science fiction programmes (programmes which we judged might include genetic themes, but which might not be indicated in their listing information).

- *Documentaries:* A total of eighteen documentaries were recorded for potential inclusion based on their description in the *TV Times*. Eleven of these were excluded once they had been watched due to the fact that they did not focus on HGR. This left us with a sample of seven documentaries.
- *TV films/drama:* Sixteen films or one-off dramas were recorded on the basis of their description in the *TV Times*. Ten were subsequently excluded after viewing, leaving us with two TV broadcasts of cinema films and four made-for-TV dramas that addressed HGR.
- *Medical dramas:* In total, fifty-nine medical drama episodes were taped and watched. These included episodes from the following series: *'A & E', 'Casualty', 'Chicago Hope', 'Doctors', 'ER', 'Holby City', 'Peak Practice'* and '*Where the Heart Is'.* In the event, none of them covered issues to do with

new human genetic research, and therefore none were included in the analysis.

- *Science fiction:* There were a vast number of science fiction series transmitted on terrestrial television in the year 2000 and it was hard to judge in advance whether they might deal with relevant themes. We therefore selected two series to monitor: *The X Files* and the *Star Trek Voyager* series. (*'Star Trek Voyager'* was chosen rather than other Star Trek series such as *Star Trek* or *The Next Generation* on the grounds that it was the most contemporary series from the Star Trek stable and therefore was more likely to contain representations of new human genetic research). Forty-seven programmes were taped and watched. Out of those, three were relevant and included in the final analysis.
- *Other TV output:* The category of 'other' was used when a programme did not fit into the formats outlined above. Comedy programmes and discussion panel programmes were included in this grouping. As with the other formats, the *TV Times* listings guide was scanned for anything that appeared relevant to HGR and the items were taped. Twenty programmes were initially taped but after viewing all but one were excluded from the sample. For example we excluded a three part discussion panel series *Hypotheticals* which focused on medical ethics, but did not address the ethics of HGR. The only relevant programme collected via this route was a panel discussion hosted by Melvyn Bragg: *The Human Genome: Can We Now Play God?* (23 July 2000, ITV).

The above sampling method was designed to be consistent across diverse media formats, easily repeatable and generated a comprehensive archive within these criteria. Our archive of non-news TV output consisted of: 7 documentaries, 2 TV broadcasts of sci-fi/horror cinema films, and 4 made-for-TV dramas, 3 science fiction episodes and 1 panel discussion programme.

(d) Monitoring other outlets: cinema, radio and magazine coverage in 2000

Finally we complemented our archive of press and TV output during 2000 by looking at three other media outlets: cinema, magazines and radio.

- *Cinema releases:* The cinema sample was based on daily scrutiny of the film review sections of the broadsheet and tabloid press to examine pre/reviews of cinema releases. This identified 4 cinema films with a HGR theme. These were then viewed and all included in the final sample.
- *Magazines:* The magazine sample was selected on the basis of market position and different readerships (using Audit Bureau of Circulations figures released for the year 2000, Jan-June 1999). The magazines we scrutinised were: *FHM* (aimed at men*), Sugar* (aimed at teenage girls*),* and *Prima, Candis, Cosmopolitan* (aimed at different adult female audiences). Hard copies of each magazine (60 issues in total) were scanned to identify items on HGR. This identified a total of 17 items. (See Appendix 5)
- *Radio:* We monitored two radio series throughout the year 2000 which were judged most likely to include items about HGR. These series were the weekly medical programme "*Case Notes*" which focuses on key issues in primary care and "*Frontiers*" which identifies 'cutting edge'

developments in the scientific research community. In addition we made recordings of any one off programmes or series where their description in the *TV Times* suggested they might address such issues. (See Appendix 5).

(e) Interviews with journalists, scientists and press officers

A case study was chosen to allow us to explore more about the production of news in relation to one particular story. The key event during the year 2000 which generated more coverage than any other was the Human Genome Project announcement about mapping 'the first draft'. This was therefore chosen as our main case study. Original press releases were examined for this case and eight tape-recorded interviews were conducted with those involved in producing the reporting. Interviewees were asked to reflect on their coverage of the human genome announcement; to contextualise that event within other more general coverage of genetic research and to outline the constraints and pressures involved in reporting these types of issues. The nine interviews involved six newspaper and TV journalists/editors, a press officers from the Wellcome Trust and the main British Scientist involved in the story: Sir John Sulston as well as one of the more critical voices cited in the Wellcome Trust Press Release, Tom Shakespeare. (For reasons of confidentiality the media personnel are simply identified by a code and their role rather than by name).

We were also able to draw on interviews with scientists and journalists from an earlier study on human genetics (in the mid 1990s) for comparative purposes. (See Kitzinger and Reilly, 1997).

(f) Monitoring the selected sample of press coverage 1997-1999

In addition to all the above data collection focused on the year 2000 we wished to contextualise our analysis of this year in relation to developments over the preceding few years. In order to do this we collected all the coverage of HGR for the years 1997-1999 from six selected UK national newspapers representing both tabloids and broadsheet and both right-of-centre, left-of-centre publications. The selected newspapers were *The Times, Independent, Guardian, Daily Telegraph*, *Mirror* and *Sun*. We used electronic databases to compile the broadsheet coverage (using the same search terms as were used on the TV news archives). However as tabloids were not available in electronic form we collected that archive by scanning hard copies of these papers. (Thanks are due to the Glasgow Media Group for access to their store of the *Mirror* and *Sun* and to Serena Patterson and Yvonne Wayne for compiling the clippings for us).

This data collection method generated a total of 622 items. Additional historical perspective is provided by drawing on our earlier study of media reporting of HGR during four months in 1994/95. (See Kitzinger and Reilly, 1997).

2.2. Coding and analysis

Each item from the press reporting (1997-1999 and the year 2000 sample) was indexed onto computer by date, headline, author, author specialism, format, page/section description and the type of visual images used (e.g. diagram of double helix, photograph of known scientist, lab scene). Each item was also coded for its 'story lead': the main focus of the article as indicated by its opening paragraph and substantive discussion in the body of the article. Categories of story leads included for example: 'Discovery and Mapping', 'Medical Applications', 'Animal-Human Genetics' and 'Cloning'. We also coded any mention of medical/environmental benefits or risks. In addition we noted and coded all statements regarding any type of ELSI such as: the rights and wrongs of commercialisation/patenting, issues around democracy and accountability, dilemmas for individuals facing genetic knowledge or the dangers of genetic determinism.

Because we were particularly interested in items which focused on ELSIs these were also subject to an extra layer of coding. For all articles which focused on ELSIs we recorded the type of 'news hook' on which the story was based (e.g. 'A report released today raises crucial ethical issues...'). In addition we coded all the people who were quoted in the report (under categories such as: 'scientist', 'Member of Parliament', 'affected lay person'). For a full copy of the coding form see Appendix 1.

Similar coding (adapted for different formats) was carried out on the TV news and non-news output and the cinema, radio and magazine items in our sample.

All coding categories were developed inductively out of scrutinising the media coverage and knowledge about media practices and forms. Careful notes were made to ensure consistent categorising of basic details such as format (e.g. whether an item was a 'column', 'editorial' or 'news report'). The research team drafted a coding frame for the substantive categories, such as ‘story lead’ and ‘types of ELSI’, by reviewing the academic literature and the year 2000 press archive to identify relevant issues and variables. The validity of these coding categories was tested independently by 5 researchers using a sub-sample of 100 articles that were selected to represent the diversity within the archive. After further discussion, a refined coding frame was agreed and a detailed, 17-page guidance manual was written to ensure consistent practice. Regular coding review meetings were used to crosscheck and maintain consistency.

This basic coding of all media items was used to provide a framework to examine our central questions. Quantitative analysis of the data based on the above coding allowed us to profile the extent and nature of media coverage of ELSIs around HGR. It also allowed us to document how coverage rose and fell over time and to explore the commonalities and differences between coverage in diverse outlets and formats and by different types of journalist.

In addition more detailed discourse/textual analysis was conducted on particular stories: the Human Genome Project story see section 3.6 and the stem-cell research story see section 3.7). This allowed us to examine how ELSIs were played out around specific stories in more detail. The interviews with journalists and their sources for the first case study also allowed us to explore how news production processes operated in this case.

The following section presents an overview of our findings in each of these key areas. (For more detailed discussion see publications). We start by summarising the shifting profile of HGR since the mid 1990s and examining the nature of the coverage in the year 2000. We then present findings from our two detailed case studies.

3. Findings

3.1. The rising profile of human genetic research and its ethical, legal and social implications from the mid 1990s.

During the second half of the 1990s and into 2000 human genetic research gained a higher profile than it had ever before, attracted more diverse forms of coverage and there was increased attention to the ethical, legal and social dilemmas such research might raise. The year 2000 in particular was a peak year for such discussion.

- In the mid 1990s human genetic research [HGR] received very little attention in the media. Our early work on coverage of HGR around health in the UK press during 4 months in 1994/95 showed that although there was a steady trickle of reports about genetic research progress (and controversies about certain genes for 'behaviour' such as the gay gene), genetic research about human health was not a high profile story. The potential ELSIs were virtually ignored (Kitzinger and Reilly, 1997). Most press reports at that time were news items simply reporting findings and framed by a straightforward discourse of 'promise' rather than risk, with headlines such as 'Scientists 'turn off' cancer gene' (*Daily Telegraph* 15 December 1994). These reports were usually no more than a few paragraphs in length and the reporting was overwhelmingly science based (often drawing verbatim from scientific press releases and using no other identified sources). (See Kitzinger and Reilly, 1997).

- When we interviewed UK journalists in the mid 1990s they themselves commented on the lack of press investigation around the issue: 'not a lot gets done [...] It's not really a big story' (Broadsheet, Science editor). Journalists who were interested in the issue found it hard to get stories in the paper. They highlighted the lack of a 'human interest' angle to frame a story and the lack of 'news events' to fuel press attention and create a 'news hook'.[2]

- In the mid 1990s journalists in the UK saw no obvious government spokespersons on genetics and few policy initiatives around this issue. As one science editor commented: 'there isn't enough interest at the top level, the political level, to ensure that serious consideration of the consequences of the science will be taken [...] As such our remit is affected by that' (Broadsheet science editor).

- The potential ELSIs associated with HGR were difficult to address within press and TV news because they were seen as almost 'science fiction'. Journalists made comments such as: the risks of human genetics research are 'speculation [...] not really news' (Broadsheet, science editor). As one journalist reflected: 'newspapers in general are very poor at looking to the future more than tomorrow's edition. If you come and say to them "I want to write a story about something that isn't a problem now but will be in five years time", they are not going to be interested' (Broadsheet specialist) (Kitzinger and Reilly, 1997)

- By the year 2000 however the situation was very different and editorial priorities had changed. There was a dramatic increase in reporting in 2000 and a shift in journalists' experience of writing about the subject.

- Major news events organised by high-profile organisations formed the basis for major news stories. In particular the announcement of the mapping of the human genome in June 2000 was seen as 'the science story of the decade' (Broadsheet science specialist).

- Science correspondents who had encountered lack of interest from their editors were now being actively encouraged to report on the HGP. As one science correspondent commented: 'I had been writing about [the HGP] since 1990 and then suddenly everybody else gets interested. Suddenly the editor gets interested and says “Why aren’t we writing about this?” […] I had given up writing news stories about it because they don’t get in and then suddenly you’ve got all the space you want. Just as you get a bit bored by it' (Broadsheet Science specialist).

- There were a total of 984 newspaper articles in the national UK press during that year including 37 editorials and 40 front-page stories. Coverage during this year was greater than it had been in any of the last three years of the 1990s. Analysis of our 6 selected newspapers (2 tabloids and 4 broadsheets) from 1997 to 2000 demonstrates that coverage in 2000 in each of these newspapers was at least double what it had been, on average, over each of the preceding years.

- There was also a broadening of the range of interest in HGR in the year 2000. In particular HGR attracted the interest of editors and column writers. Analysis of our six selected papers from 1997-2000 showed that in the last three years of the 1990s, just 4% of coverage consisted of columns/commentaries and less than 1% involved editorials. In the year 2000, however, this figure was 13% and 5% respectively.

- Science specialists themselves commented on the diverse range of reporters who were coming into the territory of HGR. This was especially true of areas in which they had kept a watching brief, such as the human genome project, but which suddenly, in 2000, became front page news. One experienced science journalist commented: 'It’s like being an anthropologist when the first package tourists arrive. You’re studying something rather obscure that you understand and a few other people understand and you try and write stories about it and suddenly other people arrive and the whole thing gets simplified.' (Broadsheet science specialist)

- Between 1994 and the year 2000 we can also see a shift in the extent to which journalists or their sources were raising concerns about ethical, legal and social risks. The earlier study of four months reporting of HGR in the mid 1990s found that most reports were positive about the research and that the idea of risk was rarely addressed. Only one headline stated that

the research might pose a 'risk', 'threat', 'danger' or peril' (Kitzinger and Reilly, 1997). In the year 2000 the situation was very different. Positive ideas were still very prominent with headlines talking of research 'breakthrough' and 'advance' (38 headlines), heralding 'miracles' (9 headlines) and providing 'hope' (36 headlines). However, alongside this, there was an increasing sense of the potential dangers. Words signalling concern appeared in over 1 out of every 13 headlines about human genetic research in the year 2000. The research was said to pose a 'risk', 'threat', danger' or 'peril' (19 headlines), it was the subject of 'warnings', 'dilemmas' and 'problems' (n= 14). It prompted 'controversies', 'crises', 'rows', and 'storms' (n=19). It provoked 'anger', 'alarm', 'dismay', 'worry', 'fear' and 'nightmares' (n=27).

- This sense of the risk/social controversy is underlined by analysis of the main focus of each article comparing 1997-1999 with the year 2000. In 1997-99, in our six selected newspapers, 25% of reports about HGR 'led' on the issue of ethics (i.e. making ELSIs the subject of the opening paragraph and including substantial discussion within the text). In the year 2000 this increased to 35% of coverage.

The broad outline above suggests that between the mid-1990s and into the year 2000 there was an increasing interest in HGR and its ELSIs. However, this was not linear. Two points should be considered. Firstly it should be noted that the year 2000 marked an unprecedented peak in interest - particularly because of the announcement from the Human Genome Project.[3] Secondly, it is important to remember that media interest ebbs and flows around key events over the preceding three years. For example the cloning of Dolly the sheep in 1997 prompted one of the first peaks of interest in the potential for human cloning and prompted extensive speculation. Headlines around the time Dolly was introduced to the world's media included:

> Why can't we clone a sheep to look like Raquel Welch (*Sun* 28 February 2000)
> Scientists 'able to create human clone' (*Guardian* 26 February 1997)
> It won't ever be a world of replicants (*Guardian* 28 February 2002)
> We can clone people claim Scots experts (*Mirror* 24 February 1997).

The *Mirror*, under the headline: 'Cloning soon for people' even invited people to vote: 'Would you allow yourself to be cloned? Vote 'Yes' 'No' by phoning following numbers' (*Mirror* 3 March 1997).

The above section has given a broad sense of how the year 2000 was positioned in relation to the preceding few years. The following section focuses more tightly on the year 2000 to give an idea of the rise and fall of reporting over the year and the way in which ELSIs were addressed.

3.2. Newspaper coverage of human genetic research: an overview of the year 2000.

3.2.1. The nature, distribution and rise and fall of press coverage during the year

There were 984 items (feature articles, news reports, editorials, columns etc) about HGR in the national UK press during the year 2000. The *Guardian* had the most coverage (n=147). Most of the other daily papers had coverage of between 90 and 115 items. There was however, markedly less coverage in *The Mirror* (n=39) and The *Sun* (n=37). In the discussion that follows we provide an overview of all the coverage across the different newspapers.

As already indicated HGR was covered in a broad range of formats during the year 2000. This included feature articles (14% of coverage in all 19 newspapers in our 2000 archive), columns or commentary pieces (10%)[4] and even book reviews (2%).[5] (See Figure 1). A broad range of writers were involved in producing these reports. General reporters accounted for 44% of the contributors. However, where items were written by specialists then science journalists account for 48% of the named specialists contributing reports, health correspondents made up another 11%. The story was also taken up by political correspondents (6%), foreign correspondents (or journalists from other countries) (7%) and there were a substantial number of columns or commentaries written either by a paper's regular columnist (6%) or by guest writers (11%). (See Figure 2).

Figure 1 showing the format of newspaper items about HGR.

Format Type	Number of Articles	% of coverage
Column/Comment	102	10%
Editorial	37	4%
Feature	136	14%
News	645	66%
Other	29	3%
Profile	18	2%
Review	17	2%
Total	984	

Figure 2 showing journalists' specialisms

Type of specialism	Number of Articles	As a % of specialist journalists
Columnist	38	6%
Editor	37	6%
Finance Journalist	2	>1%
Foreign/Abroad Correspondent	43	7%
Guest Writer	63	11%
Health/Medical Journalist	65	11%
Other Specialism	26	4%
Political Correspondent	36	6%
Science Journalist	280	48%
Unspecified/General Reporter	463	N/a
Total	1053*	

* It should be noted that some articles had more than one journalist, hence we have recorded details of 1053 journalists for the 984 articles.

There were 3 main 'news events' which attracted peak coverage during the year. The peaks of coverage are clearly visible in the chart showing the number of items in the UK national press each week during 2000, see Figure 4. In fact these three weeks contained 22% of the total coverage for the year

The greatest peak of coverage occurred in week 26 (24th – 30th June). This was prompted by the announcement of the completion of the first draft of the human genome. This generated extensive celebratory headlines, discussion of the battle between scientists to 'win the race' and debate about the commercial context of research and implications for people lives. Headlines included:

> It's one small piece of man, one giant leap for mankind (*Mirror*, 27 June 2000)
> Egos and genomes: how science got nasty. Scientists at War (T*he Times* supplement, 23 June 2000)
> Fears amid science's euphoria. You can't put a price on a human goldmine (*Daily Mail*, 27 June 2000).

[For full discussion see Case Study 1, section 3.6]

Another, smaller peak in press attention accompanied the release of the Donaldson report about 'therapeutic cloning' and using embryos in stem cell research. This occurred in week 33 (12th – 18th August). Headlines included:

> Moral dilemmas at the edges of life. (*Independent*, 20 August 2000)
> Why we must step back from the abyss. (*Daily Mail* 17 August 2000)
> It's scary, but we have to risk cloning. (*Sunday Times*, 20 August 2000)
> The benefits of cloning leave no room for doubt. (*Daily Express* 17 August 2000)

[For full discussion see Case Study 2, section 3.7]

The other major story in 2000 revolved around the Nash family case in week 40 (30th September – 6th October). This involved the announcement that pre-implantation genetic diagnoses had been used by a couple in order that they might conceive a child who could provide material for his older sister's bone marrow treatment. Headlines included:

> Baby boy 'created' so that he can save his dying sister. Birth of child with 'designer' cells sparks a massive ethical debate. (*Daily Express*, 4 October 2000)
> Baby bred to give his sister life. (*The Times*, 4 October 2000)
> 'Why I gave birth to a 'spare-part' baby.' (*Daily Mail*, 4 October 2000)

As is clear from the above headlines each of these stories raised intense debate around ELSIs around HGR and, indeed, this was a theme which ran across the coverage during 2000. The following section now takes a closer look at the profile of ELSIs within all the reporting during the year 2000.

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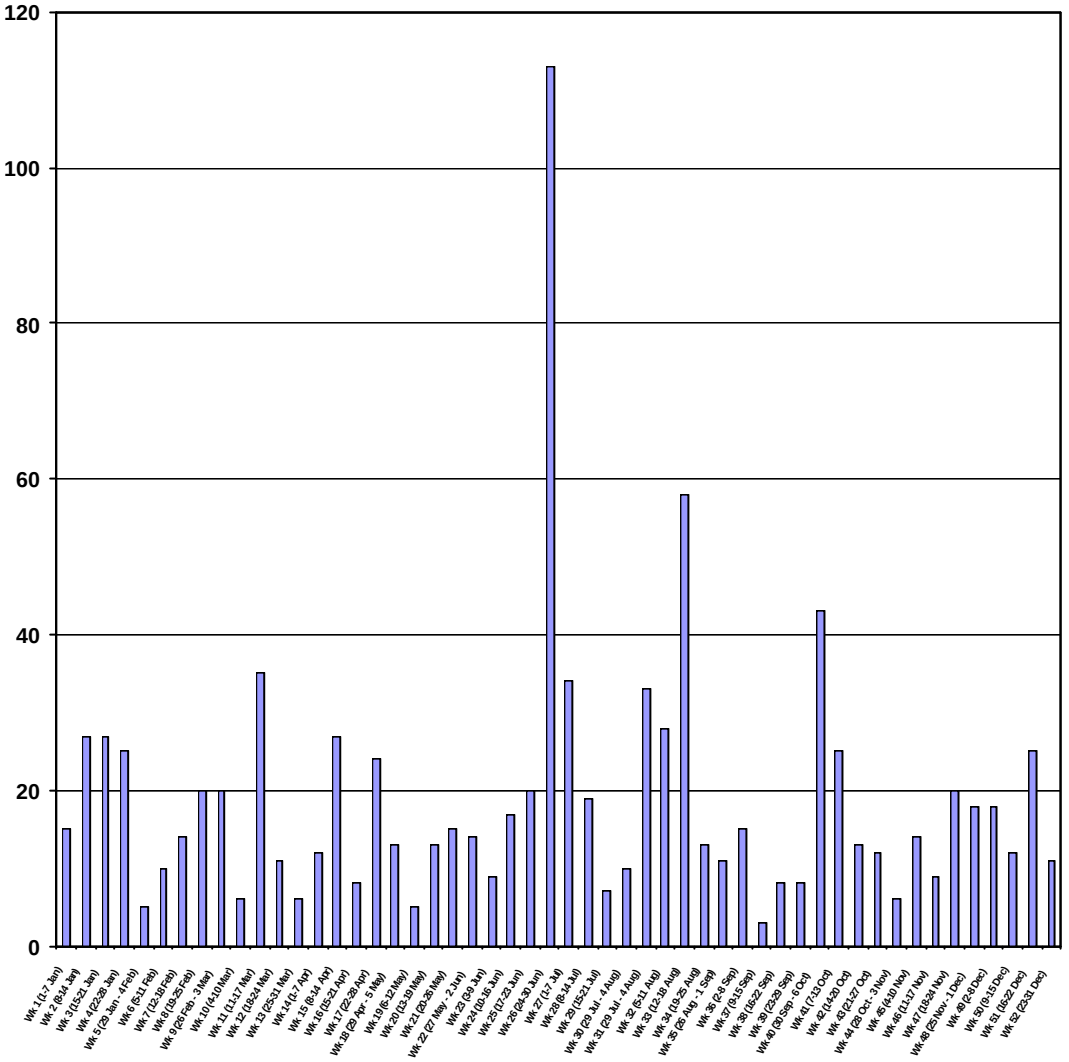
Figure 3 showing the number of newspaper reports for each week during 2000



Key Events:

Week 26 - (24th June) 'First draft of human genome announced'

Week 33 – (12th August) Donaldson report released (therapeutic cloning recommendations)

Week 40 – (30th Sept) 'Designer Baby' Nash announced

3.2.2. The profile of ELSIs in the press

Thirty six percent of articles (n=349) led on the ethical, legal or social dimensions of HGR - addressing this in their opening paragraph and including substantial discussion of the issue in the body of the article. Another 20% explicitly addressed at least one ELSI somewhere within the article. Fifty items (5%) simply included an acknowledgement that ethical issues existed, without further specification or illumination. ELSIs were not mentioned at all in 392 articles (40%). (See Figure 4). In other words most coverage of HGR included discussion of ELSIs and just over a third of items took ELSIs as their main focus.

Figure 4 showing the number of extent to which coverage addressed ethical/legal/social issues ['ELSIs']

Extent of discussion of ELSIs	Number of Articles	As % of total sample
Article 'led' on ELSI	349	36%
Article included mention of at least one specific ELSI	193	20%
Article did not specify any ELSI but did include a statement that ELSIs existed	50	5%
No mention of ELSI	392	40%
Total	984	

There was a clear pattern to the type of ELSIs which were discussed. The main ELSIs raised in the sample as a whole addressed four broad debates about:

- redesigning human life, eugenics, interfering with nature, 'playing God' (n=250, 25% of coverage);
- problems associated with the commercialisation of human genes (n=144, 15% of coverage);
- ethical debates about access to and control over genetic information (n=143, 15% of coverage);
- the problem of genetic determinism (n=95 articles, 10% of coverage).

Less prominent ELSIs, which were only occasionally raised were:

- the dilemmas individuals (as opposed to society) would face confronting personal genetic knowledge (n=55, raised in 6% of articles); [6]
- the issue of democracy and accountability around HGR (n=55, 6%);
- national economic implications (n=36, 4%);
- animal welfare (n=28, 3%);
- implications of expanding life span (e.g. for pensions) (n=20, 2%).

Figure 5 showing types of legal, ethical and social implications addressed in the UK national press during 2000

Types of ELSI mentioned or discussed	Number of Articles	As a % of all articles (N=984)	As % of articles which addressed ELSIs (N=592)
None	392	40%	N/A
Redesigning Human Life	250	25%	42%
Commercialisation	144	15%	24%
Information: Access and Control	143	15%	24%
Genetic Determinism	95	10%	16%
Other	81	8%	14%
Democracy and Accountability	55	6%	9%
Dilemmas for Individuals	55	6%	9%
Brief unspecified	50	5%	8%
National Economic Implications	36	4%	6%
Animal Welfare and Rights	28	3%	5%
Ageing	20	2%	3%
Total	1349*		

* These figures add up to more than the total number of articles, and more than 100%, as many articles addressed more than one ELSI.

All of the 349 article which 'led' on ELSIs were subject to an extra level of coding. We recorded the news 'hook' which informed each such item. This showed that almost one third of reports focused on ELSIs were based on 'news events' around scientific advances (e.g. from the human genome project). Another third were based on the release of advisory reports/policy decisions (e.g. the Donaldson report about stem cell research).

In addition we examined who was quoted in these articles. This showed that the dominant sources were scientists and policy makers (See figure 6). Twenty eight percent of the articles which focused on ELSIs included quotes from scientists or science funding bodies, 24% included quotes from policy makers. Other sources used in these articles were people directly affected by genetic 'risk factors' (10%), financial organisations (7%), religious representatives (7%), anti-abortion activists (6%), medical treatment personnel (5%) and disability activists (1%).

Figure 6 showing who was quoted in articles that led on ELSIs

Quotes Representing*	Number of Articles	As % of items leading on ELSIs (N= 394)
Scientists and funding bodies	110	28%
Policy makers	94	24%
'Affected people/patients'	39	10%
Financial organisations	29	7%
Religious representatives	29	7%
Anti-abortion activists	25	6%
Physicians/treatment personnel	21	5%
Disability activists	3	1%
Other	68	17%
No quotes	104	26%
Total	**522****	

* These categories are based on how the individual was identified in the newspaper item. For example, Professor Lord Winston could be classified as a Scientist or as a medical practitioner (or, indeed, a member of the House of Lords). The way in which his contributions was coded depended on how it was framed within the newspaper report. Similarly 'disability activists' could overlap with 'affected people/patients', however, in practice the distinction was clear. The former category applies to people who spoke from the politics of disability (e.g. around questions of eugenics), the latter category applies to people mobilised individually or collectively as 'patients'.

**This figure is higher than the 349 articles that led on ELSI, as some articles quoted from more than one source.

3.2.3. A brief reflection on differences between different formats and journalists and diverse newspapers.

- **Format differences:** ELSIs are raised more in some formats than others. The vast majority of editorial and column/commentary coverage discussed ELSIs (90 and 92% respectively). Such issues were much less likely to be raised in straight news reporting (53% of new reports mentioned ELSI).

- **Authorship differences:** There were also differences between reporting by different journalists: 56% of items authored by science journalists and 49% of those authored by health correspondents mentioned ethical implications, similarly 54% of items authored by general reporters (often unnamed) discussed ELSI. However this figure was much higher when pieces were authored by guest writers (86% mentioned ethical implications), foreign correspondents (or those writing contributions from other countries, usually the USA) (86%) and political correspondents (97% mentioned ELSIs). Where editors, columnists, guest writers or political correspondents are involved ELSIs are more likely to be addressed, The direction of 'cause and effect' here should not be assumed to be in one direction. It should also be noted that different 'types' of story mobilise different journalists - for example the HGP announcement involved political correspondents and contributors from American papers. (See case study 1, section 3.6 for further discussion)

- **Newspaper differences:** Ethical, legal and social issues were not raised uniformly across the press.

    - There were differences between the extent to which ELSIs were focused upon in different newspapers. However, this did not follow a straightforward tabloid/broadsheet or right-of-centre/left-of-centre split. In fact the two newspapers with the *highest* proportion of articles focusing on ELSIs were the left-of-centre broadsheet, the *Guardian* and the right-of-centre, middle market tabloid, the *Daily Mail*. Forty one percent of articles in the *Guardian* and 44% of those in the *Mail* focused on ELSIs. The papers with the *lowest* proportion of articles focusing on ELSIs were the *Financial Times*, *Sun* and *Mirror.* Between 23% and 24% or articles in each of these papers focused on ELSIs.

    - The *type* of ELSIs discussed however varied by newspaper. For example the *Daily Mail* often framed the ELSIs of HGR in terms of traditional morality, the sanctity of human life, family values and the dangers of 'playing God'. By contrast the *Guardian* was more likely to frame the issue in terms of social and economic systems e.g. focusing on patenting. Twenty five percent of articles in the *Guardian* discussed commercialisation, as opposed to just 6% of articles in the *Mail*. Conversely 40% of reports in the *Mail* raised questions about 'redesigning human life', as opposed to 27% of items in the *Guardian.*

    - The position taken on ELSIs also varied by newspaper. As might be expected some papers, for example, were more positive about

patenting than others (e.g. the *Guardian* versus *The Times*, see, for example, 'The Gene Frontier. Science will not be advanced by outlawing profits (*The Times*, 27 June 2000)

3.3. TV news reporting of human genetic research: an overview of the year 2000.

3.3.1. The nature, distribution and rise and fall of TV news reporting during the year.

There were a total of 44 main evening television news items about HGR in the year 2000. Twenty-three of these involved contributions from specialist reporters: usually science specialists (16 reports) but, on occasion, there were reports made by social affairs correspondents (4 reports) or medical/health correspondents (3 reports).

The three major 'news events' which attracted peak coverage in the press, also attracted peak coverage in TV news. [7] The peaks of coverage are clearly visible in Figure 7. [8] Indeed a total of 41% of the TV news coverage occurred in these three weeks alone.

The first, and largest, peak relates to the announcement from the Human Genome Project about mapping 'the first draft' on 26 June 2000. This generated lead news reports such as those below. (The quotations below are verbatim from the news reports.)

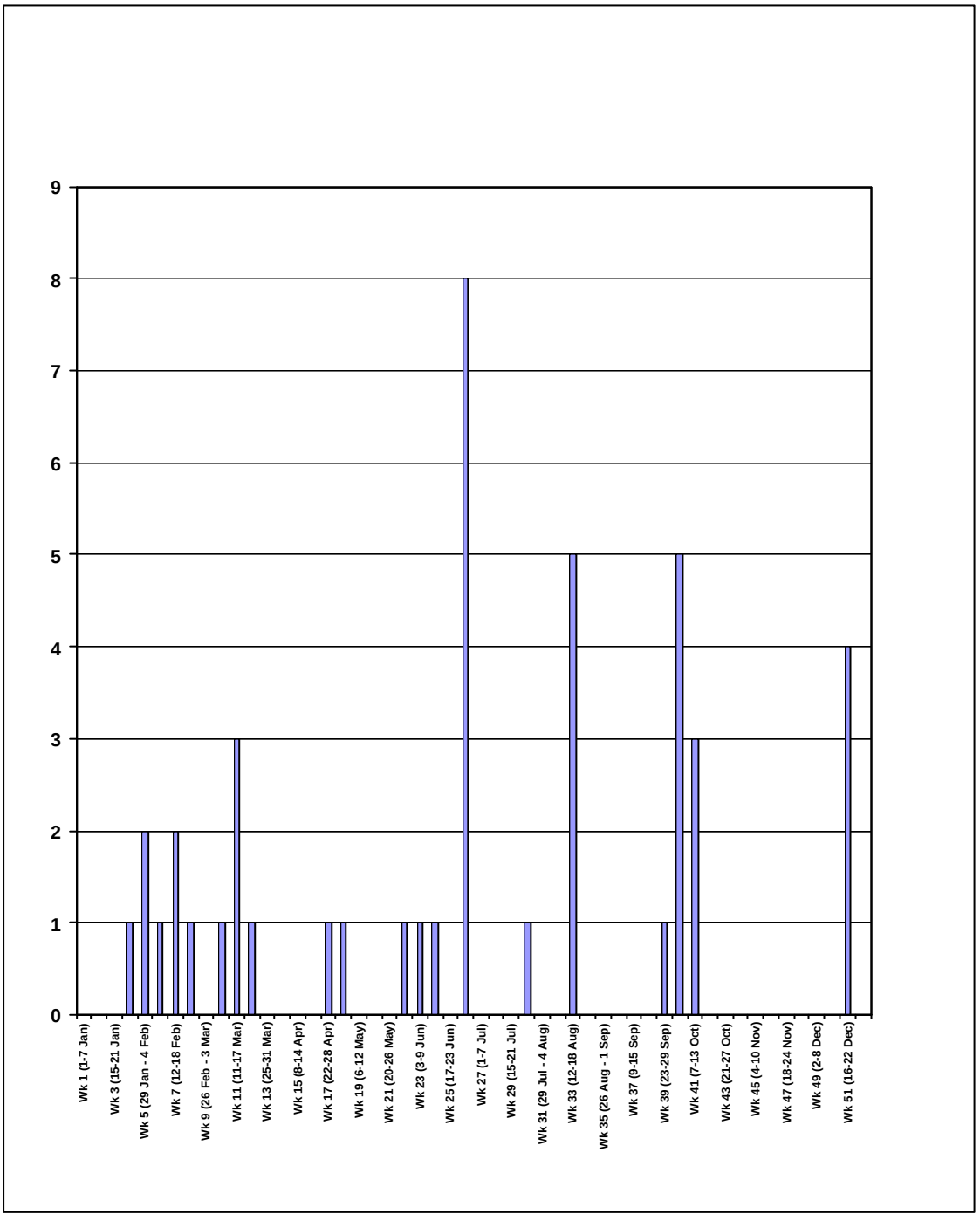
> Scientists say they've finally unravelled the genetic blueprint of mankind. The biggest medical breakthrough for a generation could cure dozens of diseases (BBC 2100, 26 June 2000).
>
> One small presidential photo opportunity, one giant leap for mankind. (C4 1900, 26 June 2000).
>
> Unlocking the genetic code. The breakthrough that's been hailed as the medical equivalent of putting a man on the moon.
> (C5 1800, 26 June 2000)

The peaks in coverage during August and then in December relate to the release of the Donaldson report making recommendations over the use of embryos for stem cell research. The report was released on 16 August 2000, its recommendations were the subject of a parliamentary vote on 19 December 2000. These two events generated a number of news bulletins opening with statements such as those below.

> The Government wants to allow embryo cloning for medical research. Should we be optimistic or alarmed?
> (BBC *Newsnight*, 16 August 2000)
>
> MP's have voted overwhelmingly to allow the use of human embryos for research into new medical treatments. Scientists hope that one-day they will be able to grow new human tissues to help treat many incurable diseases (BBC1 2200, 12 December 2000)

Kitzingerj@cardiff.ac.uk

Figure 7 showing the number of main evening news bulletins about human genetic research on television during each week in 2000.



The third peak in TV news coverage occurred in October. This relates to coverage of the 'designer baby' row. This revolved around the infant Adam Nash genetically selected pre-implantation to become a bone marrow donor for his older sister, Molly

> USA baby screened to be bone marrow donor
> (ITN Nightly News, 3 October 2000)
>
> A new creation story as Adam is born. Brought to life because he has the right genes – wonderful or terrifying?
> (BBC2 Newsnight, 4 October 2000)
>
> The baby who saved his sister but started a world-wide argument over ethics (BBC1 2100, 4 October 2000).

3.3.2. The profile of ELSIs on TV news

Thirty-one of the 44 news bulletins in our sample (71%) had ethical, legal or social issues as their main story focus. ELSIs were also the 'partial focus' of 6 bulletins and mentioned 'in passing' in 4 bulletins. Only 3 bulletins made no reference to ELSIs.

The top three ELSIs most frequently raised in the TV news coverage matched those most frequently raised in the press reporting. These were commercialisation, access and control of genetic information and the dilemmas of 'redesigning human life' (including debates about eugenics). Again mirroring the press the TV news also gave very little attention (indeed even less than the press) to issues such democracy and accountability around HGR or the implications of extending life span (e.g. for pensions). The main bulletins in our sample also did not raise some issues, such as animal welfare, at all.

Figure 8 showing the type of ELSIs reported on TV news.

Type of ELSI	No. of bulletins	As % of all reports
Commercialisation	16	36%
Information Access and Control	15	34%
Redesigning human life	14	32%
Dilemmas for individuals	7	16%
Genetic determinism	5	11%
Democracy and accountability	3	>1%
Ageing	3	>1%
Other	3	>1%

The ELSI debate on TV news was, like the press reporting, dominated by scientists and policy makers. Seventy four percent of items focused on ELSIs included quoted from scientists (or science funding bodies), 39% included policy makers. Interestingly 61% included interviews with 'affected people/patients'. This is in contrast to press coverage - a difference which is discussed in more detail in section 3.3.3. below.

Figure 9 showing who spoke on TV bulletins that led on ELSIs

Quotes Representing	Number of bulletins	As % of items leading on ELSIs (N=31)
Scientists and funding bodies	23	74%
Policy makers	12	39%
'Affected people/patients'	19	61%
Financial organisations	-	0
Religious representatives	2	7%
Anti-abortion activists	4	13%
Physicians/treatment personnel	3	10%
Disability activists	-	0
Other	14	45%
No quotes	2	7%

3.3.3. A brief comment on the differences between the press and TV news reporting of human genetic research

In many ways the press and TV reporting were very similar. Both press and television news coverage focused on the same three main stories, highlighted the same top three ELSIs and prioritised scientists as their key source. Press and TV news reporters attend the same press conferences, read the same press releases and use similar types of language in their reporting. There are, however, some differences.[9]

TV news more orientated to 'news events': The first difference to note is that although newspaper and television news reporting are both influenced by 'news values' such as timeliness, the status of sources and 'event dependency' TV news is, in some ways, even stricter in its adherence to such values. Only the most 'important' events make it into the TV news (especially the main evening news bulletins - which were the ones included in this study). This may help to explain one of the key differences revealed by our study: the fact that 44% of the TV news coverage as opposed to 22% of the press coverage occurred in the three weeks around the three major news events of the year 2000.

TV news more focused on ELSI: Interestingly, and going against the grain of some assumptions, we also found that the television news coverage actually gave *greater* attention to ELSIs than the press. Seventy one percent of TV news bulletins focused on ELSIs compared to 36% of press reporting. This may have been because the 3 key 'news events' were 3 stories which were

framed by ethical, legal or social issues at their very inception and these ELSIs were raised by high status sources (see case studies). It may also be partially due to the sampling strategy which included only the evening news bulletins. The findings may thus be more striking due to the tightly focused sample (this should be noted when direct comparisons are made between the TV and the newspaper coverage which involved a far greater sampling frame).

TV news uses more interview material: The TV news is much more likely to include quotes (in the form of interviews or 'talking heads') than the press. Television producers are, of course, acutely aware of the visual nature of their medium (and of the need for news 'balance'). Few bulletins rely solely on journalists talking to camera without attempting to interview a scientist in a laboratory, include shots from a press conference or talk to a 'patient', as well as include a voice from 'the other side'. Our analysis showed that 26% percent of newspaper articles did not include a quote from anyone. However only 7% of news bulletins failed to include interviews with anyone.

TV news gives more of a platform to 'affected people/patients': Any comparison between TV and newspapers has to take into account the different nature of the medium. The fact that TV news bulletins were much more likely to include interview material in the first place partly accounts for some difference in the frequency with which some speakers appear. Hence news bulletins were between 2 and 3 times more likely to include interviews with scientists, twice as likely to include interviews with treatment personnel and one and a half times more likely to include interviews with policy makers than the newspapers were. What is striking, however, and a clear break in this pattern, is that the TV news was *6* times more likely to include interviews with 'affected people/patients'.[10] TV news, in fact, unlike the press, gave more of a voice to the patients than to policy makers. Many bulletins included lengthy interviews with 'sufferers' about their lives, and hopes for the future. In spite of TV news having a reputation for relying on high-status sources, it is also clearly influenced by 'human interest' values. Perhaps related to this, the TV news gave far greater attention to the dilemmas which individuals would face when confronting personal genetic knowledge. This issue was addressed in 16% of news bulletins compared with just 6% of newspaper articles.

3.4. A brief reflection on media news values: predictions in 1994/5 and the shape of coverage in 2000

The research we conducted in the mid 1990s concluded by identifying HGR as a 'risk story in waiting' and predicted that developments in three areas would attract more media attention (Kitzinger and Reilly, 1997). The three potential future developments which we hypothesised would cause peak media coverage were: the announcement of scientific breakthroughs, major policy decisions, and the realisation of practical applications. These were the criteria which, we argued, would bring HGR in general, and ELSIs in particular, more into the headlines (see Kitzinger and Reilly, 1997). The diagrams above (Figure 3 and 7), and the events which linked to each peak, seem to nicely illustrate each of these three classic 'news values'. The peak

around the Donaldson Report is a classic 'policy decision' issue. The peak, around the Adam Nash case, is a story about an actual implementation of genetic knowledge for medical purposes. The HGP announcement is a classic 'scientific breakthrough story' (Although, as we show in our case study of the human genome project, this is more complex than at first appears).

3.5. A postscript about 'risk' and medical/health/environmental implications.

A key finding to emerge from our analysis of both press and TV news reporting is that 'risk' was largely discussed in terms of ELSIs, not medical or environmental risks. The discussion of 'hope' and 'fears' was thus markedly asymmetrical. This is in marked contrast to other comparable debates. Over the last few years, when GM food/crops have been discussed in the UK, extensive attention has been given to health and environmental risks. By contrast, debates about health and environmental risks have been notably muted in the coverage of *human* genetic research. This is in spite of one death in a gene therapy trial.

Seventy one percent of articles about HGR in the year 2000 mentioned potential health benefits. Only 9% mentioned potential health (or environmental) risks. There was some overlap here, so another way of looking at these figures is to note that seventy three percent of press articles (n=715) about HGR discussed its implications for health (see table 8). The vast majority of these (623 i.e. 87%) simply mentioned health *benefits* with no suggestion of any potential risks.[11] A further 75 articles mentioned potential benefits but also mentioned potential risks (11%). Only 17 reports discussed risk, without mentioning benefits.

A very similar pattern is evident in the TV news reporting. Thirty-seven out of the 44 TV news bulletins in our sample discussed the health implications of HGR. The majority of these, 32 news bulletins (87%) only discussed the medical *benefits* of HGR with no mention of any potential risks. Four bulletins discussed *both* the medical benefits and risks of HGR (11%). There were no bulletins which *only* discussed the risks of HGR.

Our analysis confirms previous work highlighting that news reporting rarely raises technical questions about the risk, reliability and safety of genetic interventions in medicine (Durant, Hansen and Bauer 1996: Peterson 2001).

The next few sections focus on our two case studies.

3.6. A case study of the Human Genome Project Announcement

On the 26 June 2000 the teams involved in mapping the human genome announced to the world's media that they had completed the 'first draft'. Widespread coverage of this 'landmark' in HGR was characterised by the discourses of hope and fear: on the one hand the media presented an optimistic future of post-genomic medicine and, on the other hand, they highlighted a pessimistic vision of post-genomic society. The following summary explores how these themes were played out in the national UK press and TV news reporting during the fortnight around the announcement.

The Human Genome Project [HGP] announcement was a carefully managed event involving very prestigious source activity. The dawning of the post-genomic era was heralded in simultaneous, video-linked press conferences in Washington and London, involving Prime Minister Blair, President Clinton and a host of leading public and private sector scientists.

The choice of date for the announcement was not determined by the science but by liaison between the key players partly in response to the efforts of American company, Celera Genomics, headed by Craig Venter to position themselves as 'ahead' of the HGP. This also influenced the emphasis of press packs e.g. "because of the private project as well, Celera, …one of our key messages was that the information was free and publicly accessible so scientists all over the world can use this for the greater good" (Wellcome press officer)

Peak media coverage occurred in the two weeks: Monday 19 June to Sunday 2 July 2000. The subsequent figures are all based on the 118 articles which appeared in the UK national press during this fortnight and the 8 main evening television news bulletins during the same time period.

- The prominence of the 'first draft' in the UK press was demonstrated by its coverage in all national UK newspapers, including 7 front page stories, 10 editorials and 8 special features that fortnight, as well as being subject of extensive coverage on every terrestrial channel's main evening news and on 'Sky' television news (the non-terrestrial channel included in our sample).

- The 'first draft' was portrayed as a watershed in history. The human genome was presented through the metaphors of a map, blueprint, software, key, recipe, code and book; the 'breakthrough' in mapping was compared to the greatest moments of social, artistic and scientific 'progress'. Analogies included: the invention of the wheel, the moon landing and the 'discovery' of the 'New World', the revolutionary ideas of Copernicus, Newton, Darwin and Einstein, the artistic creations of Shakespeare and Bach. In addition, President Clinton was widely quoted stating: "We are learning the language in which God created life." The historical associations, the use of language and the range of metaphors all implied an optimistic view of scientific progress. Many of these metaphors,

analogies and the use of time lines can be traced to press pack material e.g. produced by the Wellcome Trust.

- Cancer cures and longevity took centre stage as the medical promises of the post-genomic era. Headlines and opening statements on the TV news included: 'Scientists say they've finally unravelled the genetic blueprint of mankind. The biggest medical breakthrough for a generation could cure dozens of diseases' (BBC 2100, 26 June 2000); ' Gene code could beat all disease' (The Sun, 26 June 2000); 'Cancer may soon be a thing of the past' (Daily Express, 27 June 2000). Journalists said that they were careful to avoid 'over hyping' the findings. However, there was, for some journalists, a tension between this and the wish to make the science relevant to people's everyday lives and show how it might impact on their health in the future or the health of their children.

- Much of the media coverage also raised concerns. Headlines and opening statements on the TV news included*:* 'Barcoded at birth. Would anyone have let Beethoven do music if they'd known he'd go deaf? (Channel 5, 26 June 2000*);* 'Human Genome: the future. Could this be the answer to all our ills... Or a sinister Pandora's box? (Telegraph, 27 June 2000); The secret of life. The genome brings hope - and fear (Guardian, 26 June 2000).

- Over half of the newspaper articles (55%) focused either primarily or partially on the ELSIs of HGR as did 6 out of the 8 news bulletins.

- The HGP announcement actually served as a platform for journalists to focus *more* extensively and more intensively on particular ELSIs than they had in other reporting about human genetics.

- In particular the HGP announcement brought issues of genetic determinism to the fore because it was presented as a 'blueprint' of a human being. Twenty five percent of articles about the HGP announcement critically addressed the question of 'geneticisation' (compared to 10% of articles over the year as a whole). In fact this issue was the main focus of several articles. Headlines included 'We are bigger than our genes - thank God' (*Sunday Times*, 2 July 2000): 'Genomania: a fire that needs dousing' (*Daily Telegraph*, 1 July 2000). (This is particularly interesting in light of accusations against the media that they promote the 'geneticisation' of life).

- The very hyperbole surrounding the HGP announcement also set the scene for some more critical or reflective reporting. The promise of imminent tests raised questions about how individuals would deal with such knowledge, and the promise of a vastly expanded life span opened up the debate about the pros and cons of this. On the one hand the HGP announcement was accompanied by headlines making claims such as: 'Genes will makes us live 'for 1,200 years' (Sunday Times, 25 June 2000), on the other hand this prospect was not always welcome. Although some headlines triumphantly claimed 'living forever' as a panacea, the social and

personal realities of longevity stimulated critical questioning: 'Who wants to live forever' (Sunday People, 2 July 2000); 'Would you want to live to be 250?' (Daily Star, 27 June 2000); 'A century not out' (Daily Express, 27 June 2000). The social dilemmas associated with longevity, such as employment, housing, public health and the economy were raised in 8% of articles around the HGP announcement (but only in 2% of articles over the year as a whole). Articles on ageing openly questioned the social value of science by rhetorically asking if *quantity* of life was more valuable than *quality* of life. In contrast to previous findings (e.g. Nelkin & Lindee 1995; Conrad 1997, 1999a) some press reporting did question the social value of genetic science.

- Science journalists were acutely aware that this wasn't a simple 'science' story. 'It wasn't finished. It was an arbitrary date for publication. I mean the whole thing was hype. But we were much more interested in what was leading up to that and the battle of the patenting and whether it was going to make money" (TV reporter). 'The [June 26th announcement] was orchestrated for political and commercial reasons (Broadsheet Science Editor).

- The social/political/economic context of genetic research and its implications were highlighted in coverage of the HGP announcement to an extent, and in ways, which it had seldom been before. Concerns about the commercialisation of genetic science appeared in 41% of all newspaper articles about the HGP compared with 15% of press coverage in the sample as a whole. Debates about access to and control over genetic information appeared in 36% of newspaper articles about the announcement compared with 15% of press coverage over the year as a whole.

- Framing the story as a 'battle' between Venter and Sulston was a common strategy which helped to dramatise some of the issues about information access/control and commercialisation. Headlines included: 'Locked in battle for key to life' (Mirror, 21 June 2000); 'Scientists at War Two projects, two views of science' (The Times, 23 June 2000); 'The miraculous map of mankind. Behind the breakthrough, scientists at war' (Daily Mail, 27 June 2000). Journalists used Venter and Sulston to characterise the conflict. Nine articles profiled or interviewed these men; Venter's image appeared fifteen times, Sulston's fourteen. Their beliefs were consistently portrayed as being diametrically opposed: 'John Sulston: altruist or moralist? Craig Venter: maverick or monopolist?' (Guardian 26 June 2000); 'war veteran fights ex-hippie over 'Book of Life'" (Daily Telegraph, 27 June 2000).

- Journalists saw the opposition between these two key players as a great opportunity in media/news value terms: e.g. "You had two fantastic characters. … (John Sulston) is a natural and … a brilliant scientist…. Craig Venter himself is very media savvy but comes across as a very different personality to an English audience. […] it was certainly very easy to set one against the other in cinema terms and word terms. I think in that

case it was fair to do it because there were very different philosophies at work and Craig and John personified those two philosophies' (TV Science editor). 'Because of the characters and the race and Venter in particular, it meant that the coverage was more extensive than it would have been. People find science quite hard I think so if there are personalities to identify with it makes it easier for the readers definitely".(Broadsheet Science Editor).

- This reduction of the issues to personal antagonism was influenced by the operation of news values that rate conflict and 'real' people as more interesting than consensus and 'impersonal' organisations. On the one hand it opened up the discussion to questions of funding, ownership and commercialisation that placed the science into its economic and political context. On the other hand, it was presented very much within science's own terms. As Tom Shakespeare commented: 'The debate was presented as the 'good guys' versus the 'bad guys. The scientists say 'Yes there are ethical concerns but not with us - Celera, *they* are the people to be anxious about. The old distancing effect.'

- Some issues were, still marginalized in the reporting of the HGP, as they were in coverage over the year as a whole. Issues such as civil liberties, surveillance and the complications that human genetics poses to the legal and medical professions were largely absent. Religious and animal advocacy worldviews were only given fleeting attention as were 'global' concerns about 'bio-piracy' and health inequalities. The potential for genetic science to become the basis for weapons technology was completely absent. Even those articles that addressed the social value and utility of genetic knowledge rarely confronted the current 'therapeutic gap' between genetic diagnosis and medical interventions (Shakespeare 1999) or the opportunity costs of genetic research in the funding of public science and healthcare (Lippman 1994)

- Although extensive concerns were raised about *social* issues reporting rarely raised any concerns about environmental or medical risk. Most newspaper articles (92 out of the 118) discussed potential medical implications. However, of these 92% reported only the medical benefits and just 8% mentioned both medical benefits and risks (none only mentioned risks). A similar pattern was evident in the TV news coverage – all 8 bulletins about the HGP announcement in our sample discussed potential medical implications and highlighted benefits, but only 1 mentioned that there might also be potential medical risks. The focus on benefits and virtual exclusion of medical risks is thus greater within this case study than in was in the year as a whole. This may have been influenced by the HGP's context as 'breakthrough' science.

- Articles about the Human Genome announcement that led on ELSIs contained 69 direct quotes and the three largest sources of these were research scientists and science funding bodies (33%), policy makers/politicians (23%) and financial organisations (10%). Other sources such as 'affected people/patients', religious representatives, medical

personnel and disability activists, physicians were quoted in only between 2% and 5% of coverage. A similar pattern was evident in the TV news. In fact, in keeping with standard media theory, the TV news reporting of the ELSIs around the HGP announcement displayed even more reliance on elite sources: mainly scientists or representatives from science funding bodies, President Clinton and Prime Minister Blair.

- This finding confirms other analysis which highlights the media's reliance on scientific and political sources (Cunningham-Burley, Amos and Kerr 1998; Conrad 1999b; Nelkin 2001; Nerlich, Dingwall and Clarke 2002). The novelty of this case study was that these sources were shown to be dominant in coverage of the ELSIs. It shows *how j*ournalists reporting on the 'first draft' used the project's proponents to explain and illustrate its potential for having harmful affects. On the one hand this demonstrates the high profile given to ELSIs by those working in the field and shows that the HGP announcement was used by them as an opportunity to address some of these concerns. Indeed the impetus behind the announcement was intricately tied in with their concerns about who should have access to such information and how (see earlier section). On the other hand it raises the possibility that scientific and political sources involved in the HGP might emphasise the aspects of social concern that suit their needs at the time and that can be addressed by legal and regulatory frameworks rather than raising more fundamental challenges. The content analysis certainly suggests that some concerns and some voices are still marginalised within the debate. The question of how much attention they 'should' be given, however, is in itself the focus of controversy. (For fuller discussion see Smart, 2003).

3.7. A case study of the Stem Cell Research debate

Although we had originally planned to do just one case study within the Wellcome grant, we decided to include a second example for contrast and to explore a very different type of story. Our first case study had focused on the announcement of a scientific breakthrough (the HGP), our second case study examined coverage of policy making in the form of reporting around the Donaldson report, and the subsequent policy decision.

We chose the stem cell debate for more detailed analysis because it attracted peak media attention and because it raised intense debate about research ethics. We collaborated on the following analysis with Wellcome research fellow: Clare Williams.

In addition to the type of coding carried out on the sample as a whole this case study involved in-depth textual analysis in order to how the embryo was described, including the use of different terminology and visual images and all references to its significance, status and size. We also examined how the embryo was positioned in the narrative: its origin and potential and relationship to others. Close attention was given to the ways in which journalists or the sources they cited defined 'life' and the metaphors used for the stem-cell research endeavour. We also examined the presentation of the potential beneficiaries of stem-cell research. Finally the data were systematically re-examined to clarify apparent gaps - including, for example, to identity the ways in which women appeared (or not) in the debate. All exceptions to the dominant patterns in coverage were also re-examined.

The following summary addresses the broad nature of the coverage, the competing discourses which were mobilised within it and the issues which were marginalised. We then briefly reflect on some of the media values which helped shape the coverage of HGR in general, and of this issue in particular and the implications for encouraging public debate about the ELSIs of HGR.

3.7.1. The broad framing, structure and balance of coverage

- The stem-cell debate was framed as, above all, a controversy about the status and potential of the embryo (rather than, for example, the validity of the science per se or the context in which it was being realised).

- The reporting was structured around a polarised opposition between two sides. On one side were those who felt embryonic stem-cell research was an abuse of embryos which set dangerous precedents (e.g. for reproductive cloning), on the other were those who argued that the benefits of such research outweighed any ethical dilemmas or risks (if such dilemmas or risks existed at all).

- There was a very tight casting of opponents. The 'pro' position was promoted predominantly by scientists/doctors, Labour politicians and the type of patients who might (eventually) benefit from stem cell research. It is particularly striking that no one speaking against stem cell research was

identified as a scientist or doctor in the press coverage. The voices speaking out *against* stem cell research came from Conservative MPs, religious figures and anti-abortionists.

- There was, at least superficially, an effort to give equal platforms to these opposing voices. The roughly balanced number of articles containing quotes 'for' and 'against' stem cell research, and the roughly balanced time allocated to both sides on television is testimony (782 seconds v 652 seconds) to the media's effort to represent the conflict.

- The extent to which the reporting itself was *'balanced'* in relation to the controversy however is a different matter. TV news anchors adopted their usual role of neutrality, however many newspaper journalists and editorials overtly displayed allegiances in *favour* of embryonic stem cell research. In addition, subtle prioritising of a pro stem cell research agenda was evident across the coverage even where no explicit allegiance was declared.

3.7.2. Competing discourses in the stem cell coverage

Proponents and opponents of embryonic stem cell research mobilised contrasting discourses about the embryo, the research, and the potential beneficiaries. These revolved around the following:

- **The 14-day time limit:** Proponents of stem cell research used the 14-day time limit as a mantra to guarantee moral boundaries would be maintained. This time limit was presented as a technical, scientific 'truth'. However, this cut off point was ignored or explicitly rejected by opponents.

- **The question of size**: Proponents of stem-cell research emphasised the microscopic size of the embryo to emphasis its non-person status. By contrast size was only subject to comment by opponents on one occasion - in order to emphasis the embryo's vulnerability as 'a tiny human being'.

- **The battle of images:** The use of images and visualisation in the stem cell debate contrast sharply with the use of images in previous debates about the embryo - namely the abortion debate. In the stem cell debate it was *proponents* of stem-cell research who repeatedly highlighted the physical appearance of the pre 14 day old embryo (' balls of cells...no arms and legs') ('like fluorescent frogspawn'). By contrast 'defenders' of the embryo did not reference its physical appearance at all. Whereas images of 12-week-old embryos with tiny fingers and toes are used in one context to assert its human status quite the opposite is happening in this case. Here the image of the pre-14 day old embryo is used to underline the fact that these cells should not, indeed *can* not, be recognised as human.

- **Source, destiny and social embeddedness of the embryo**: Proponents repeatedly declared that the cluster of cells would be 'left over' from IVF whereas opponents spoke of embryos being deliberately 'manufactured' (emphasising the CNR option). Where proponents of stem cell research talked of cells which would otherwise be ‘discarded’, their opponents

implied they would, in the 'normal' course of events, become a person. Where proponents of stem cell research used clinical language about embryonic cells their opponents evoked parent-child relations with words such as 'cherish', 'protect' and 'nurture'. Whereas one side positioned the embryo in petri dishes, frozen vats or clinical waste disposal units, the other implicitly presented the embryo nestled in a womb (although this womb, and the woman it belonged to was never explicitly acknowledged).

- **Biographical versus biological vitality**: Running through the debate was a struggle over the definition of human life, and death, itself. Opponents repeatedly spoke of embryos being 'killed' but proponents only used alternative words such as 'dismantling' or even talked about the cells actually achieving 'immortality' through the research. (see Walby 2002:313).

- **Metaphors for the science:** Metaphors were woven through out the stem cell debate - most strikingly in relation to how the science, and scientists, were represented. Stem cell research was repeatedly characterised by supporters as a new 'frontier' for 'pioneer' science. In contrast, opponents evoked a different kind of boundary crossing - not the bold adventurers of frontier pioneers bringing civilisation but an illegitimate invasion: 'raiding', 'plunder'. Some went further and used metaphors that involved the breaching of the most fundamental boundary of all: 'cannibalism'.

- **Introducing the potential beneficiaries:** Proponents of stem cell research presented it as promising great benefits. This was not just argued in abstract, viewers/readers were invited to identify with specific individuals. Where embryos were presented by supporters of stem cell research as free-floating, disembodied, non-sentient and anonymous cells - abstracted from all social context - patients were introduced as firmly embodied individuals, experiencing intense physical and emotional sensations, and deeply embedded in family relations. Audiences were explicitly invited to weigh one against the other. One man with Huntingdon's disease filmed for the BBC news, for example, presented viewers with a stark choice: 'It's either me or an egg.' (*BBC1 9pm News* 16 August 2000).

3.7.3. Marginalised discourses in the stem cell coverage

The controversy around as played out in the terms outlined above effectively sidelined other potential debates. The gaps we documented include:

- **Lack of attention to the therapeutic gap or medical risks.** In a total of 8 news bulletins and 55 newspaper articles there were just 2 occasions when the 'therapeutic gap' was highlighted as a *problem*, rather than an opportunity for hope. There were only 4 occasions when there was any mention of potential physical risks in stem cell based therapies.

- **Sidelining wider social and political context.** There was very little attention to how 'choice' would operate for patients in the future and how

medical innovations would actually be delivered within the global health economy. For example there were just five, in passing, references to 'commercial pressures' in the press reporting and a brief exchange during one TV studio discussion. Revealingly this tentative discussion which emerged in the studio was quickly redirected by the news anchor with the question: 'that balls of cells…does it deserve no respect?'.

- **Marginalising women's voices.** Women's voices, regardless of whether they were opponents or proponents of stem-cell research, were much less prominent than men's in this debate. Newspaper articles written by men out numbered those by women by eleven to one. Male speakers were given almost twice as much time on TV news as female speakers and were quoted in the press four times as often.

- **Marginalising women as 'subjects'.** Women were presented in the passive tense, not as actors in the process. Their role as sources of eggs or embryos was obscured (in both text and images). In all the coverage there was just one clear example of women's active participation being addressed. This was Leah Wild's *Guardian* column documenting the progress of her IVF treatment. Commenting on the stem cell debate she remarked: 'in all this furore, these is one voice missing: mine. The majority of embryos for research come from people like me'. She went on to write about the complexity of her own feelings about donating and presented some of the deep sense of connection with the embryos that donors might experience even while supporting such research. This exceptional example of such a 'voice' highlights its exclusion from the rest of the debate and hints at some of the complexities that were thereby ignored.

3.7.4. A brief reflection on the limits of the public debate and media factors which influenced this

Many policy makers are concerned to encourage wide-ranging debate about medical and scientific innovations. There was a deliberate effort to facilitate this around the stem-cell issue. In some ways this was successful with competing voices about the embryo being given extensive consideration in the press and TV news coverage. However our analysis shows that, although on the surface, a major controversy was 'aired', many fundamental questions remained unexplored and some voices were excluded from the frame.

Many factors influence how the stem cell debate played out within the media. Some of these are external to the media (e.g. the organisation of groups for and against stem cell research and their lobbying/P.R. activities). However, it is worth commenting on the contributing role played by media factors. These are outlined below.

- **News reporting is oriented toward high status sources and 'events' (rather than issues).** The reporting of stem cell research during the year 2000 was prompted by the release of the Donaldson report and the subsequent parliamentary vote. It follows that, as both events focused on the status of the embryo, this would powerfully define the terms of the

subsequent debate. Unless some of the issues which were marginalised in the stem cell debate during 2000 become framed as 'news events' it will be difficult for them to gain sustained or high profile coverage.

- **Press and TV news journalists like to include 'human interest stories'.** 'Hard' news values, such as those outlined above, are now increasingly complemented by 'soft' human interest stories with greater 'entertainment' value and high appeal to audience identification (Henderson and Kitzinger, 1999). This was very much in evidence in the coverage of stem cell research. The attention and prominence that the news media were predisposed to give to personal accounts from 'patients' meant that proponents of stem-cell research had extra leverage with the media.[12]

- **The news media is male dominated.** Gender inequalities are threaded through media organisations, values, practices and hierarchies (see Kitzinger, 1998). This contributed to/exacerbated some of the gender politics and contributed to the marginalisation of women.

- **News reporting often is attracted to polarised oppositions in preference to exploring complexity and nuances.** The media framed the issue as a 2-sided controversy with stock characters 'for' and 'against'. This is a standard way in which the news media frame stories and time/space limitations encourage 'sound bite' exchanges between opponents. This didactic and dyadic framing contributed to the exclusion of some more nuanced, complex debates.

3.8. Beyond the news: documentaries and fiction

The above discussion has focused on news reporting (whether in the press or on television) and 'news values'. This final section briefly discusses documentaries and fiction.

3.8.1. Documentaries

There were seven documentaries focusing on HGR within our 2000 sample (see Appendix 2).[13] Two of these focused entirely on specific ELSIs: gene patenting (*Designing Our Lives: The Patent,* BBC2, 15 May 2000) and gene 'prospecting' (*The Gene Hunters*, Channel 4, 8 September 2000). Another explored the debate between those promoting the medical benefits of genetic research and those opposing it on ethical grounds (*Correspondent Europe: our genes*, BBC2, 6 May 2000). The remaining four documentaries were all primarily focused on the positive medical potential of gene research. One was about a rare genetic condition (*Horizon: Moon Children* (BBC2, 4 April 2000) and three formed part of Robert Winston's series: *Superhuman* (BBC1, 29 October, 12 November and 19 November 2000). Analysis of this sample suggests the following:

- Documentaries provided the opportunity for more in-depth coverage than TV news or press reporting. The average length of the programmes was 46 minutes. Documentaries also follow different genre conventions which offer different challenges and opportunities, see Corner et al. 1990.

- On the one hand many of the issues covered in the documentaries echoed the debates in the news media. Like the news coverage the focus was on medical benefit (even while addressing ethical, legal or social risks) with any potential medical *risk* only being mentioned (briefly) in one programme.

- However, the pattern of coverage was slightly different from news coverage (TV and press) in some respects. In particular, the focus on medical applications meant that, overall, there was a more extensive platform given to 'ordinary people' within the role of patients (a typical anchoring device in documentaries, see Corner et al, 1990). For example, *'Horizon: Moon children'* focused mainly on children with XP and their families, highlighting the difficulty they face getting through day to day life. The focus on how HGR might directly affect 'real people' also involved some discussion of individual dilemmas - an area relatively unexplored in the press coverage (although subject to more discussion in TV news). (See, for example, discussion of the dilemmas facing someone who has a test to determine whether they are pre-disposed to cancer in 'Superhuman: 'The enemy within').

The documentaries will be analysed further in future publications.

3.8.2. Fiction: a different space?

The discussion so far has focused on factual reporting (news and documentaries). However, no review of the representation of HGR would be complete without also considering fictional representations.
There is, of course, a long history of scientists in general, and scientific experiments on human beings in particular, featuring in fictional story-lines (Tudor, 1989; Turney, 1998). Such cultural repertoires are often referenced in discussion of HGR among the 'lay public' as well as by policy makers (Wellcome Trust, 1998; Mulkay, 1996). Indeed fiction may be particularly significant in engaging broad audiences, inviting emotional identification with characters and resourcing the imagination (Henderson, 2002; Henderson and Kitzinger, 1999).

We are not suggesting a direct relationship between fictional representation and public beliefs or policy outcomes.[14] Here we simply wish to acknowledge that, fiction is arguably *as* important as factual reporting in public discourse around genetics. At the same time it is important to acknowledge that fictional representations are often very complex and multi-layered, and that its 'influence' or 'uses' can be equally complex (see Mulkay, 1996; Schlesinger et al., 1992).[15]

During the year 2000 HGR featured as a story-line in four cinema releases and nine fictional programmes broadcast on TV. The cinema films involved three in the action/sci-fi/horror genre (e.g. *The 6th Day*) and one comedy (*The Nutty Professor 2*). The television programmes involved two TV broadcasts of sci-fi/horror cinema films, 3 science fiction episodes and four made-for-TV dramas. The TV fictional output analysed for our study are listed in Appendix 3, the cinema releases are summarised in Appendix 4.

Our analysis highlights the following:

Highlighting ELSIs

- HGR is a popular theme in fiction - being used in 13 fictional programmes/films during the year 2000.

- Fiction gives greater emphasis to ELSIs compared to news reporting. ELSIs were the main focus in 8 out of the 13 fictional programmes/films and at least raised in every one.

- Fiction also places emphasis on *different types* of ELSIs than news reporting. In particular fictional output included substantial discussion of 'Democracy and Accountability' - this issue was sidelined in the press and TV news reporting but discussed at length in fiction such as *Blade Runner, Futurecast* and *6th Day*. Similarly individual dilemmas which had very little discussion in the press, although rather more on TV news, was explored at length in various fictional programmes such as *Blade Runner, Cloned, Natural Selection, The Fly, Futurecast, X-Men, 6th Day.*

Highlighting risk

- Whereas the factual reporting (press and TV news and documentaries) rarely envisage science 'going wrong' and leading to physical environmental risks, this is not true in fictional output. For example in *Bladerunner* the replicants become a physical threat to human and in *The Fly* a monstrous man-fly hybrid is created by accident.
- Whereas the press and TV news treat scientists treated with some respect and attribute them with a degree of rationality and authority this is not the case in some fiction. Scientists are presented as obsessive/ narrow thinkers/ driven mad by their own power e.g. The Scientist in *The Fly* and *Hollow Man*, and the *Nutty Professor* who goes against advice (and is a figure of fun).
- Whereas press/TV news present regulations and the importance of informed consent as potential safeguards, however, in fiction the rules, if they exist, are broken dramatically (e.g. the secret and corrupt cloning in *Cloned* and in *The 6th Day* without the consent of the people involved).
- Some novel discussion also occurred within fiction such as reflection about what counts as a 'rogue' gene. For example the film *Nutty Professor 2* highlights the danger of removing 'rogue genes' when Dr Klump loses part of his intelligence alongside extracting a 'bad gene' and in *Startrek Voyager* it is the 'defective gene' which allows its carrier to save the ship.

Linking the past, the present and the 'imminent' future

Fiction can invent plot lines which make explicit and concrete links which might only be abstractly evoked in factual reporting.

- Two of the films used plot devices which explicitly linked genetic research with Nazism. In *Silent Witness* - the expert in genetics experimented on twins in the concentration camps during the war; in *X-Men* the first scenes are set in Poland in 1944. We see Jews marching to the gas chambers and the child who escapes becomes the vengeful mutant who develops the machine to mutate all ordinary humans.
- A crucial aspect of fiction, in the context of our research, is its ability to be set in the future. Futuristic dramas, including science fictions, can dramatise and conjure up a future which has not yet occurred. Whereas predictions about the future within factual outlets maybe explored as 'speculation' or assessed for 'realism', fiction can conjure up and portray the potential future at length in a quite different framework even while invoking these futures as 'possible'. This device was used in several of the films locating the story within viewers' life time. *Futurecast* was set in '2012'; *Bladerunne*r in 2019 while *The X-men* was set 'in Mississippi, 'in the not too distant future'.
- This projected future is sometimes given greater power by being explicitly linked with the present. *The 6th Day* starts by flashing up headlines on screen 'Scientists clone a sheep named Dolly'; *Futurecast* similarly explicitly linked with present; while the *X- Men* had first scenes set in Poland in 1944 explicitly rooting its main character of the future in a real past.

Exploring fundamental themes about identity, humanity and society

The overlap between different fictional output is striking. It affords an up-to-date opportunity to explore many traditional dramatic themes ranging from family tensions (see Henderson and Kitzinger, 1999) to questions about identity, humanity and the dangers of human being interfering with the gods. (These are themes which have a long history and which may even be traced back to Greek tragedies) (see Turney, 1998). Some of the films echoed themes such as 'Frankenstein' (*The Fly*) or Jeckyll and Hyde (*The Nutty Professor*) or reworked themes from previous futuristic fiction such as 'Brave New World' or '1984' (*Bladerunner).* Themes running across fictional output include, for example:

- *Reflection on questions of Identity:* The crew of the Star ship are in fact clones but only discover this later in the day ('Course Oblivion' 16 July 2000); the replicant woman does not realise she is not human (*Bladerunner*); Adam in *The 6th Day* discovers, half way through film, that he is a clone while in *Natural Selection* the main character Ben discovers he, and his best friend, are clones.
- *Reflection on who or what counts as 'human'*: In *Bladerunner*, for example, the main character, Deckard's, task of tracking the Replicants and then killing them is called 'retirement' by the humans. The use of this term brings to light the issue of power and rights. Because humans created the Replicants, they have the right to control their lifestyle and life span. After killing a Replicant Deckard says: "The report would be routine retirement of a Replicant, which didn't make me feel any better about shooting a woman in the back."
- *Struggle between social groups and questions of discrimination.* Many of the fictional representations show genetically altered or cloned individuals being created for slave labour or treated as an underclass and show their efforts to fight back. In the *X files*, aliens are carrying out genetic research on humans so they can have a slave race, (*X - Files*, 8 July 2000, BBC1). In *Bladerunner* the replicants are treated as an underclass. In the *X-men* there is a movement to rid the planet of mutants and in *The 6th Day* the clones are allowed no rights.

Fiction formats and conventions

Fictional programmes potentially offer 'larger', or at least different, spaces for discussion compared to both news reporting and even documentaries. Typically fictional episodes about HGR lasted between half an hour and two hours rather than the few minutes or single page awarded to HGR in television news press reporting. Fictional films are also usually longer than documentaries. The average length of the 13 fictional episode/films in our sample was 97 minutes, the average length of the documentaries was half of this, 46 minutes. The greater time is, of course, used to do much more than discuss 'the topic'. It should not simply be considered as 'more' space, but be recognised as a different type of space within which the genetic research issue is embedded (allowing for evolving narratives, characterisation, twists in the tale etc.)

Fiction offers different opportunities/constraints from factual programming such as documentaries. It appeals to a different type of 'authenticity'.[16] There are crucial genre and production differences between different types of fictional output. At the level of broad generalisation, however, fiction is different from factual representation because it typically gives greater emphasis to:

- entertainment rather than information
- emotion and drama
- dramatising dilemmas
- exploring inter-personal relationships
- developing characterisation and appealing to identification
- exploiting narrative tensions, twists and turns over the course of the programme
- Sustaining contradictions/complexity (e.g. between different characters' perspective or even involving characters changing their allegiances)
- Where story-lines were split across a series there was also use of 'cliff hangers' to draw viewers into watching the next part (e.g. 'Silent Witness). (See Henderson 2002 for detailed study of the production values informing how serious issues are addressed in fiction, specifically drama serials/soaps).

These dimensions were all prominent within the fictional TV broadcasts and the cinema films in our sample and can contribute to a different way of representing debate around ELSIs. For example:

- Fictional coverage often involves the playing out of dilemmas/different points of view in a more complex way than the straight forward head-to-heads in press debates, TV news, discussions or documentaries. Fiction can allow for characters changing their point of view, or audience sympathy being drawn toward characters in different ways. For example, the issues of exploitation in collecting DNA for research, and genetic 'cleansing' are highlighted by a series of short films within-the-film 'Futurecast'. And the dialogue between competing perspectives is played out in the conversation between the kidnapped scientist and his captors.

- Fiction is able to, and does, portray different type of actors compared to press and TV news reporting (see Henderson 1996). In the case of fiction around HGR the most notable difference from other reporting is the prominence given to citizens / protestors. There were only two visual images of 'protestors' in the 984 newspaper items during 2000. By contrast protestors featured in walk on roles in several of the fictional programmes. Protestors against mutants appeared in *X-men* and demonstrators in *World Cruise* carrying banners with slogans such as 'Hands off our DNA' while *Futurecast* showed footage of mass demonstrations for access to genetic medicines. Activists were also central characters as the kidnappers in *Futurecast* and also appeared in the cloning film *6th Day*.

4. Conclusion

This research has established a unique archive of UK media coverage of new human genetic research over an entire year. Importantly we have included electronic as well as print media, and fictional as well as factual programming. This allows for a broader understanding of the media's role. We have also examined how reporting has changed over time (since the mid 1990s) and thus avoided presenting a static picture of coverage.

Systematic analysis of this archive has produced a quantitative framework for locating qualitative based critiques of media coverage (e.g. the debate about media 'hype' or promotion of 'genetic determinism'). Our work both supports and challenges, or at least contextualises, some existing theorising. It certainly suggests that it is important to acknowledge both the *extent* and the *limitations* of the ways in which the contemporary media have presented some of the potential ethical, legal and social implications of human genetic research.

Our research has identified the way in which reporting of HGP has evolved since the mid 1990s, with the year 2000 seeing the topic 'come of age' within diverse media, and with extensive attention to ELSIs. It demonstrates how certain events, we predicted to have high news-value (scientific announcements, policy decisions, and actual applications of the research), materialised during 2000 and attracted peak media attention. We have explored how these were translated into 'stories' through source activity (rhetoric, self-presentation, press conferences) and how they were processed through journalistic practices and new values. We have examined, for example the impact of news reporter's orientation toward high status sources and 'events' (rather than issues) and how this worked in combination with a predilection for 'human interest interviews' to privilege some voices over others. We have also highlighted how the routine framing of debates in terms of polar opposites can erase complexity, nuances and ambivalence. Above all we have shown how, although some ELSIs have now become 'mainstream', others are still marginalised. Although there is extensive discussion of potential ethical, legal or social consequences (the main focus of over 1 in 3 articles during 2000), there is very little discussion of potential medical/environmental risks (mentioned in just 9% of coverage). Even within discussion of ELSIs it is also clear that certain issues remain systematically silenced within most news reporting. Issues such as democracy and accountability, for example, were mentioned in just 6% of newspaper reports and less than 1% of TV news bulletins. There was, nevertheless, evidence that some formats within TV news or newspapers offer greater potential than others for addressing the more unwieldy or novel debates of accountability, value, need, risks and costs of HGR.

Fiction, we have argued, provides a very different type of space for the representation of HGR and its potential ELSIs. Fictional coverage was much less deferential to science and scientists, powerfully dramatised some ELSIs that received less exposure via news formats, and explored in-depth

imagined futures which might be dismissed as 'mere speculation' within factual reporting. Fiction was also used to explore ambivalence in a way often absent from news formats. Fictionalised representations of genetic research also were more likely to portray lay people as citizens/protestors rather than only as 'patients' (as was typical within news formats).

The *influence* of the different types of coverage outlined above can not be assumed a priori. It will depend, in part, on how audiences respond to such coverage, in particular the different ways in which people 'make sense' of factual and fictional representation reception processes. (This 'audience reception' part of the circuit of mass communication was not included in this research - but which could be fruitfully explored in any future work). What counts as *'good'* coverage will, of course, also depend on whose perspective we are considering. The aim of this study has been simply to outline the broad nature of coverage of HGP and its ELSIs in recent years and to identify the patterns and variables within it and some of the factors which impact upon this. We hope that in this way our research will help to inform the on-going debate and contribute toward innovations in media representation of, and increasing public engagement with, science.

For full discussion of findings and case studies please see publications below.

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5. Output

Publications

- *'Reporting the dawn of the post-genomic era: who wants to live forever?'* Sociology of Health and Illness 25(1): 24-49. Smart, A.

- *'Envisaging the embryo in stem cell research*: *discursive strategies and media reporting of the ethical debates'* Sociology of Health and Illness, *25(7): 793-814.* Williams, C. Kitzinger, J. and Henderson, L.

- Henderson, L and Kitzinger, J (2007) *" Orchestrating a science 'event': the case of the human genome project*" New Genetics and Society. 26 (1): 65-83.

For update on publications see staff websites at Cardiff and Brunel

Presentations at conferences outside the UK

- *'Barcoded at Birth? UK Media Coverage of the Human Genome Project'* S4 conference, Society for Social Studies of Science, 5-9 Nov 2002, Milwaukee, USA (Kitzinger, J)

- *'Communicating Science: the case of human genetics'*, 23rd Conference and General Assembly, IAMCR/AIECS/AIERI, Barcelona, 21-26 July, 2002 (Henderson, L)

- *'Media reporting of risk'*, Risk Journalism conference, Lusófona University, Portugal, October 25th, 2002 (Kitzinger, J)

UK based conferences/seminars

- *'Constructing and deconstructing the 'gay gene': mass and minority discourses and media debates'* The 45th symposium of the Society for the study of human biology 'Ethics and human biology: diversity, difference and deviance' 23-24th Sept 2002, London (Kitzinger, J)

- *'Unveiling the Genome: Coverage of the ethical, legal and social implications of the Human Genome Project'*, Institute of Genetics, Biorisks and Society seminar on Nottingham University 14 March 2002. (Smart, A)

- *'Who wants to live forever? Press ambivalence to the Human Genome Project',* Brunel University seminar series, 2 October 2003 (Smart, A)

- *'Embryos, ethics and stem cell research: UK media constructions of the debate'*, Who Twists the Helix? A trans-disciplinary exploration of the powers that could decide our genetic futures, The University Centre, University of Cambridge, March 16-19, 2003 (co-authored with Clare Williams)

- *'Innovative medical gene technologies and images of the embryo'* submitted to 'Innovating Medicine: medical technologies in social sciences, University of Manchester, July 2003 (co-authored with Clare Williams)

- Also organised: *'The Role of the Media: Controversies About Human Genetic Research'* ESRC sponsored workshop, 2 February 2001, Brunel University (speakers included: Dorothy Nelkin, Pat Spallone, Tim Radford, Barney Wyld, Alastair Kent, David King)

Cont.

Output cont.

Further research initiatives

- We successfully bid for a three year ESRC-funded study to examine the media framing of risk which will build on the above content analysis across a range of social and science subjects.
  Kitzinger, J and Murdock, G (starting Oct. 2003) 'Media framing of Risk'. ESRC, £202,000.

- The senior research fellow on this project, Dr Lesley Henderson, is preparing a Wellcome fellowship application to expand on this work

- We are preparing an application to the AHRB to examine audience responses to fictional representations of HGR

6. References

BMA (1992*) Our Genetic Future*, Oxford University Press.
Condit, C. M., Ofulue, N. and Sheedy, K. M. (1998) Determinism and mass media portrayals of genetics, *American Journal of Human Genetics*, 62, 97984.
Condit, C (1999) book
Conrad, P. and Weinberg, D. (1996) Has the gene for alcoholism been discovered three times since 1980? A news media analysis, *Perspectives on Social Problems*, 8, 3-25.
Conrad, P. (1997) Public Eyes and Private Genes: Historical Frames, News Constructions, and Social Problems, *Social Problems*, 44, 139-54.
Conrad, P. (1999a) A Mirage of Genes, *Sociology of Health and Illness*, 21, 228-41.
Conrad, P. (1999b) Use of expertise: sources, quotes, and voice in the reporting of genetics in the news, *Public Understanding of Science*, 8, 285-302.
Conrad, P. (2001) Genetic optimism: Framing genes and mental illness in the news, *Culture, Medicine and Psychiatry*, 25, 225-47.
Corner, J.,K. Richardson and N. Fenton: "Nuclear Reaction. Form and Response in Public Issue Television". Acamedia Research Monograph 4, 1990, London: John Libbey.
Cunningham-Burley, S., Amos, A. and Kerr, A. (1998) *The social and cultural impact of the new genetics.* Edinburgh: Department of Public Health Sciences at The University of Edinburgh.
Deckett, A (2003) *Audience responses to a fictional programme about human genetic research and its implications*. Brunel University Undergraduate project. Unpublished.
Durant, J., Hansen, A. and Bauer, M. (1996) Public Understanding of the New Genetics. In Marteau, T. and Richards, M. (eds) *The Troubled Helix: the social and psychological implications of the new human genetics.* Cambridge: Cambridge University Press.
Henderson, L (2002) *Social Issues in British Soap Opera* PhD thesis, Glasgow University
Henderson, L (1996) 'Selling Suffering: Mental Illness and Media Values' in G. Philo (Ed) *The Media and Mental Distress*, Addison, Wesley, Longman
Henderson, L and Kitzinger, J (1999) The human drama of genetics: 'hard' and 'soft' media representations of inherited breast cancer', *Sociology of Health and Illness, 21(5): 560-578.*
Hansen, A., & Dickinson, R. (1992). Science coverage in the British mass media: Media output and source input. *Communications*, 17(3), 365-377.
House of Commons Science and Technology Committee (1995) *Human genetics: the science and its consequences,* London: HMSO.
Hansen, A. (2000) Claims-making and framing in British newspaper coverage of the "Brent Spar" controversy. In S. Allan, B. Adam, C. Carter, *Environmental Risks and the Media*. London: Routledge.
Hubbard, R. and Wald, E. (1997) *Exploding the gene myth: How genetic information is produced and manipulated by scientists, physicians, employers, insurance companies, educators and law enforcers.* Boston: Beacon Press.

Kitzinger, J (1998) 'The gender-politics of news production: silenced voices and false memories' in Carter, C, Branston, G and Allan, S (eds) *News, Gender and Power*, London: Routledge. pp186-203.
Kitzinger, J & Reilly, J (1997) 'The rise and fall of risk reporting' *The European Journal of Communication* 12(3): 319-350.
Macintyre, S (1995) The public understanding of science or the scientific understanding of the public? A review of the social context of 'the new genetics', *Public Unders. of Science,* 4, 223-232.
Macintyre, S (1996) Social and ethical Issues in the new genetics. In Peckham and Smith *The Scientific Basis of Health Services*. BMJ pub..
Miller, D., Kitzinger, J., Williams, K and Beharrell, P. (1998) *The circuit of mass communication*. Sage.
Mulkay, M (1996) Frankenstein and the debate over embryo research', *Science, Technology and Human Values*, 21.
Nelkin, D. (1987) *Selling Science: How the press covers science and technology.* New York: W H Freeman and Co.
Nelkin, D. (2001) Beyond Risk. Reporting about genetics in the post-Asilomar press, *Biology and Medicine*, 44, 199-207.
Nelkin, D. and Lindee S. (1995) *The DNA Mystique: The gene as a cultural ic*
Nelkin, D and Lindee, S. (1998) Media Portrayals of Genetics*, American Journal of Human Genetics*, 63, 662-3.
Nerlich, B., Dingwall, R. and Clarke, D. D. (2002) The book of life: how the completion of the Human Genome Project was revealed to the public, *Health,* 6, 445-469.
Nuffield Council on Bioethics (1993) *Genetic Screening, Ethical Issues*.
Schlesinger, P. Et al, (1992) *Women viewing violence.* London: Bfi.
Peterson, A. (2001) Biofantasies: genetics and medicine in the print news media, *Social Science and Medicine*, 52, 1255-1268.
Philo, G (ed) (1999) *Message Received*. Longman
Shakespeare, T. (1999) 'Losing the plot'? Medical and activist discourses of contemporary genetics and disability. In Conrad, P. and Gabe, J. (eds*) Sociological Perspectives on the New Genetics.* Oxford: Blackwell.
Shuchman, M. and Wilkes, M. S. (1997) Medical scientists and health
Stockdale, A. (1999) Waiting for the cure: mapping the social relations of human gene therapy research. In Conrad, P. and Gabe, J. (eds*) Sociological Perspectives on the New Genetics.* Oxford: Blackwell.
The House of Commons Science and Technology Select Committee **(**1995) *Report, 'Human Genetics'*
Tudor, A (1989) *Monsters and mad scientists: a cultural history of the horror movie.* Blackwell.
Turney, J (1998) *Frankenstein's footsteps,* Yale University Press.
Waldby, C. (2002) Stem cell, tissue cultures and the production of biovalue. *Health*, 6, 305-323.
Wellcome, 1998 *Public perspectives on Human cloning*. London: The Wellcome Trust
Wilkie, T (1993) *Perilous Knowledge: the human genome project and its implications,* Faber.

Appendix 1 Example of a coding sheet

Newspaper: **Date:**
Headline:
Name:

Specialism

Columnist/ Editor/ Finance Journalist/ Foreign Correspondent or 'Abroad'/ Guest Writer/ Health or Medical Journalist/ Other Specialism/ Political Journalist/ Science Journalist/ Unspecified or General reporter

Format

Cartoon/ Column or Comment/ Editorial/ Feature/ News/ Other/ Profile/ Review

Page or Section Description

Arts or books/ City and Finance/ Comment and Analysis/ Front Page/ Health/ News/ Other/ Science and Technology/ Unknown/ Women

Story Lead

Animal-Human Genetics/ Cloning/ Discovery and Mapping/ Ethical, legal & social implications/ Financial Implications/ Medical Applications/ Other/ Reproductive Genetics

Type of Images

Animal/ Cartoon/ Demonstrators/ Double Helix/ Explanatory Diagram/ Medical or Treatment scene/ Portrait of known scientist/ Portrait of lay people/ Portrait - Other/ None/ Other/ Scientist or laboratory scene/ Under the Microscope

Medical Repercussions Benefit/ Risk/ Both/ None

Types of ethical, legal & social implications:

Ageing	Genetic Determinism
Animal welfare and rights	Information: Access and control
Brief unspecified	National Economic Benefit
Commercialisation	None
Democracy and Accountability	Other
Dilemmas for individuals	Redesigning Human Life

Hook

None/ Other/ Policy or advisory report/ Science publication, conference or announcement

Quotes representing

'Affected people/patients' (inc. family & charities)/ Anti-abortion activists/ Disability activists/ Financial organisations/ None/ Other/ Physicians-treatment personnel/ Policy makers/ Religious representatives/ Scientists and funding bodies.

Appendix 2 Documentaries during 2000

Documentaries about human genetic research in our 2000 sample

Horizon: Moon Children (BBC2, 21:00-21:50 04 April 2000)
About a rare genetic condition (Xeroderma Pigmentosum).

Designing Our Lives: The Patent (BBC2, 19:30-20:0015 May 2000)
About the patenting of life, and the ethical or moral issues surrounding this possibility

Correspondent Europe 'Our Genes' (BBC2, 18:50-19:35, 6 May 2000)
About competing arguments between the possible medical benefits of new human genetic research and the ethical concerns.

The Gene Hunters (Channel 4 03:50-04:40 08 September 2000)
Following a group of geneticists into Columbia where they take DNA from some remote tribes, for a 'DNA Bank'.

Superhuman 'Self Repair' (BBC1, 21:10-22:00, 29 October 2000). Explaining the medical and scientific applications of genetic research.

Superhuman 'The Enemy Within' (BBC1, 21:10-22:00, 12 November 2000)
About cancer and its genetic associations

Superhuman 'The Baby Builders' (BBC1, 21.10-22:00, 19 November 2000)
Focussing on how early human life develops and how science can change or manipulate this process.

Appendix 3 Summary of fictional output about human genetic research broadcast on terrestrial TV

Cinema films broadcast on TV during 2000:

- *'The Fly'* (Originally cinema released in 1986. Shown on BBC1 on 21 July 2000). The story of a scientist who accidentally genetically fuses himself with a fly.
- *'Blade Runner'* (Originally cinema released in 1982. Shown on Channel 4 on 15 July 2000). A retired bounty hunter is coerced by the police into tracking down and destroying a gang of renegade 'replicants' on the loose in Los Angeles.

Science fiction TV series:

- *Star Trek Voyager: 'Course Oblivion'* (16 July 2000). The Ship's crew discover they are really clones.
- *Star Trek Voyager: 'The Fight'* (23 July 2000). Commander Chakotay experiences hallucinations because of a genetic 'defect' which actually turns out to be a positive ability to communicate with aliens who help Voyager escape danger.
- *The X files, 'Two fathers/one son' (8 July 2000, BBC1).* Aliens are carrying out genetic research on humans so they can have a slave race, but human beings combat this with research using alien DNA.

Other made-for-TV fictional output

- *'Cloned'*, (Made for TV, originally released in 1997, Shown on Channel 5 on 6 March 2000). A couple discover that their only child, conceived through IVF treatment and now dead, was actually illegally cloned 12 times. The mother tracks down the clones and sets out to expose the company and the scientist responsible.
- *'Natural Selection'* (Made for TV, originally released in 1994. Shown on BBC1 on 24 April 2000). The story of Ben, who discovers he is a clone. One of his clones, 'Simon', is systematically killing off all the clones and taking on their identities. The film climaxes with a fight scene between Ben and Simon, in which one of them dies, and the audience is left not quite knowing which one is left alive and living as Ben.
- *Silent Witness 'The World Cruise' parts 1 & 2.*[17] (11 and 12th December 2000, BBC1). HGR is a sub-plot. In the main plot, people are mysteriously dying from what is eventually discovered to be lethal injection. One of the victims is a respected geneticist who, it turns out, experimented on twins in Nazi Germany. Scenes includes lectures by this geneticist and the questioning of his work.
- *Futurecast 'Kidnap'* (20 April 2000, Channel 4). A man with leukaemia and his wife, with the help of a TV programme maker, Sepp, kidnap a doctor who works for a leading multinational pharmaceutical company. They are challenging a system which prevents the man obtaining gene therapy for his leukaemia because he can not afford it. The whole event is broadcast to the world, as Sepp hacks into a news programme.

Appendix 4 Summary of cinema films featuring HGR released in 2000.

- *X- Men* (Director: Bryan Singer, 104 minutes, Genre: Action/Sci-Fi0 Tagline: 'Trust a few. Fear the rest' and 'The future is here'. The film "X-Men" was the major blockbuster cinema release in the year 2000. Aimed at school students the film develops characters drawn from classic Marvel comic book stories and animation. In the future, there are children born with an "X factor" in their genes, giving them special powers (flight, telekinesis, laser beams from eyes). Known as 'children of the atom' they are persecuted by humans. One group of mutants band together as the X-men and fight for peaceful co-existence with other humans. However, one mutant Magneto (driven by revenge after his family are killed by nazis) plots to mutate all other humans, making everyone equal and the story focuses on the battle between good and evil mutants.

- *The 6th Day (*Director: Roger Spottiswoode, 123 minutes, Genre: Action/Sci-Fi). Tagline: 'Are you ready!' Are you who you think you are?' 'You've cloned the wrong man'. In a future world, cattle, fish and family pets can be successfully cloned but cloning humans is illegal. A helicopter pilot survives a near fatal accident and returns home to discover that he has been replaced by a clone. The protagonist, played by Arnold Schwarzenegger then finds himself in a conspiracy about clones taking over the world. When those behind the cloning discover that he has survived, the action focuses on Schwarzenegger saving himself from replicant assassins.

- *Nutty Professor 2: The Klumps (*Director: Peter Segal, 106 minutes, Comedy). Tagline: 'The Klumps are back! This sequel to the Nutty Professor is a slapstick take on Dr Jekyll and Mr Hyde. Professor Sherman Klump (Eddie Murphy) is about to be married but his alter ego Buddy Love keeps resurfacing at inopportune moments. Klump attempts to use his colleagues cutting edge research on 'gene targeting' to rid himself of Buddy Love but discovers that there are serious and damaging consequences of removing 'rogue genes'.

- *Hollow Man (*Director: Paul Verhoeven, 112 minutes, Genre: Horror/Sci-Fi). Tagline: Think you're alone? Think Again'. Hollow Man, explores the repercussions of a genetic scientists search for the formula for invisibility. The protagonist played by Kevin Bacon is portrayed as an archetypal 'mad scientist' who becomes dangerously focused on his research. He successfully makes animals invisible but then insists on becoming the next test subject. The scientist becomes invisible but slowly becomes insane and begins to stalk the members of his research team.

Appendix 5 Magazines and radio coverage of HGR in 2000

Magazine coverage: There were 17 items about HGR within our magazine sample during the year 2000. Five items were located in magazines targeted at women (3 in *Candis*, 1 in *Sugar* and 1 in *Prima*). Twelve items appeared in men's magazine *FHM* (10 in a special feature on genetic inheritance entitled 'Dad's legacy FHM August 2000). A flavour of the coverage is provided by the introductory paragraph to the FHM feature:

> Almost every day some horn-rimmed test tube wielder identifies a gene responsible for making you susceptible to something, whether it be heart disease, a drinking problem, or in growing toenails. Which means that if you suddenly turn schizo, or get ball cancer, it could be your unavoidable destiny, as decided when your dad shot his man-juice into your mum. The science of genetics is still in its early stage, but here's what the boffins already know. And it doesn't make for pretty reading... (FHM, August, 2000).

Magazines have a particular way of targeting audiences and conventions. The coverage in magazines was sharply distinguished from other coverage. Every single item in magazines focused on the discovery of genes rather than any other aspect of HGR. Item covered, for example the 'gene for stupidity' (FHM October 2000), breast cancer (Candis August 2000) and autism (Prima May 200). None discussed the ethical, legal or social implications of genetic research.

Radio coverage: Our radio sample did not include any substantial discussion of new human genetic research or its ELSIs although several included references to genetics in passing. In one programme we recorded, *'Case Notes'*, genetics were mentioned simply as brief asides within discussions of wider ranging issue. For example, one programme mentioned that "good genes" play a role in long term illness (Radio 4, 2 May 2000) another stated that allergies may be caused by an interaction between allergens and genetic predisposition (Radio 4, 9 May 2000). One episode of the series '*The Enemy Within*' (Radio 4, 22 February 2000) focused on the workings of the human immune system specifically in relation to human organ transplants. In the context of examining the case of donor organ rejection the programme interviewed a patient and scientists about future research possibilities, namely xenotransplantation and embryonic cell reprogramming. Dr Harry Griffin, Assistant Director of the Roslin Institute who took part in the programme was quoted thus "Clearly this raises substantial ethical issues. It also raises major practical issues because there is a great shortage of human eggs. One of the characteristics of the cloning technique is that we know very little about it. We don't know how it works, there is a lot of work to be done…". The future of research in the area of re- programming cells was described by Dr Griffin himself as "X Files stuff".

The programmes we examined on the radio tended to be focused on medical applications and implications for policy and practice. At this stage it may be too soon to see new human genetic research within these sorts of programmes.

Endnotes

[1] We would like to thank work-placements students who assisted us with some of this very time-consuming data collection and indexing. Particular thanks are due to Angela Deckett for her skillful and thorough work on the TV archive and the data base.

[2] We also identified 96 letters. These have been analysed separately.

[2] Special thanks to Jacquie Reilly who conducted many of these interviews. For full report of the method for that study see Kitzinger, J & Reilly, J (1997) 'The rise and fall of risk reporting' *The European Journal of Communication* 12(3): 319-350.

[3] As one journalist interviewed in 2002 commented: “I think the problem now is how to keep on reporting now that people feel the job is done. The post genomic work is fascinating but there’s a slight problem now with the follow up because there probably won’t be another moment as big as the stage managed completion so the biggest thing is its harder now to get stories in” (Broadsheet science specialist).

[4] This is a slightly different figure than for the 6 newspapers that we used to compare 1997-99 coverage and 2000 coverage because it is based on all 19 newspapers in our 2000 archive.

[5] The existence of 17 reviews (of books about HGR) reflects the development of a popularised version of genetic research. The reviews include books such as: The *Second Creation: The Age of Biological Control* by Ian Wilmut, Kevin Campbell and Colin Tudg (2000); *Brave New Worlds: Genetics and the Human Experience* by Brian Appleyard (2000) and *It Ain’t Necessarily So: the Dream of the Human Genome and Other Illusions* by R Lewontin. (2000)

[6] This minimal coverage of dilemmas for individuals supports Kitzinger and Reilly’s (1997) suggestion that, while research remains at the discovery stage, insight into the personal implications of medical genetics remain a marginal concern for the news media.

[7] Other bulletins were prompted by issues/activities such as: pre-publicity or controversy around the human genome project, a battle over the patent on one of the 'breast cancer genes' and a parliamentary vote about insurance companies access to genetic information on potential clients. Headlines from these sort of stories included: 'The promised revolution in medicine from the unravelling of the human genetic code suffered a set back today when behind the scenes talks aimed at forging a public-private alliance to speed up the process collapsed. (Channel 4, 6 March 2000); 'The government is to approve the use of genetic tests by insurance companies to identify people with hereditary diseases. Insurers will be able to use the results when deciding whether to offer cover.' (BBC1, 21.00, 12 October 2000): 'Who Owns Life? The Cancer Research Campaign is taking an American genetics company to court to prevent it charging massive license fees for testing British patients for breast cancer. The company, Myriad genetics, own US patents on two breast cancer genes used to test hundreds of women at high risk of the disease'. (Channel 4 2 February 2000)

[8] In general, the profile of the TV news bulletins echoes the profile in the press reporting, except that there was no marked peak around the MPs vote around the

Donaldson recommendations in the press reporting as many journalists felt they had already tackled the issue in their August coverage.

[9] Other differences include the fact that newspapers encompass diverse formats (e.g. the column or feature article) which allows for other types of less 'news oriented' criteria to come into play. (Although TV news may have the 'light relief' item at the end of a bulletin and clearly often has a 'human interest' angle). It is also worth noting that a few minutes in a TV bulletin may also be less amenable to conveying scientific facts than a few columns in a newspaper - both because of space and format. As one TV news science correspondent commented: “You can do a lot more science in print. Television is terribly bad at getting across the facts, you can get over impressions and feelings and sights and sounds. Facts are very difficult to convey especially if its in a 4 minute, 6 minute or even 10 minute television item. ... They [the print media] have the advantage of being able to say “this is the science” even if its in a sidebar you know “this is what genes are”. “This is what you can do with it”. (TV science correspondent).

[10] Another way of looking at this information is by simply looking at items which did include quotes (i.e. excluding those which did not, thus taking into account that fact that the TV news, in the first place, included more interview material). The information is presented in this form below.

Quotes Representing	**As % of press items leading on ELSIs which quoted anyone - 290**	**As % of TV news bulletins leading on ELSIs which quoted anyone - -n=29**
Scientists and funding bodies	38%	79%
None	-	-
Policy makers	33%	41%
Other	24%	48%
Affected people/'patients'	14%	66%
Financial organisations	10%	0
Religious representatives	10%	7%
Anti-abortion activists	9%	14%
Physicians/treatment personnel	7%	10%
Disability activists	1%	

[11] This was particularly true of articles that had a story lead of medical applications, only a few articles in this category mentioned any type of medical risk.

[12] 'Affected people/'patients' were very much used to represent the ‘human face’ of hope. Within the 8 main TV evening bulletins in our sample there was not a single interview with a disability activist - framed as such rather than as a ‘disabled’ or ‘at risk’ individual who would benefit from the HGP. (Although, on one occasion Tom Shakespeare was interviewed speaking as a bioethics expert).

[13] There was also one discussion panel programme *The Human Genome: Can We Now Play God?'* (ITV, 23:15-00:20, 23 July 2000) hosted by Melvyn Bragg involving scientists, ethicists and a minister. We have not analysed this as we had no other examples.

[14] As Turney points out: 'They are no more likely simply to imbibe the typical message of straight science reporting […] than they are to leave Kenneth Branagh's film clamouring for all the laboratories to be closed down. There are always contending interpretations available, if not within a particular text then from other parts of the media landscape, or from the individual context of consumption.' (Turney, 1998: 215)

[15] The caveat about media 'impact' applies to all the research reported in this document - it is based on analysis of media content - audience reception research would be needed fully to explore the media's role in public perceptions. Two pilot focus groups conducted by a work placement student on the project suggest something of the complexity and sophistication with which people may view fiction. (see Deckett, 2003).

[16] Although, as we have argued above and elsewhere, these areas also exploited in news reporting and documentaries and there is often a blurring of the line between fact and fiction; see above and see also Henderson and Kitzinger, 1999.

[17] This counts as one programme in our figures.
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