

Current Statistics of Externally-Sponsored Research

As shown in Table 3, five ECs have been reviewed eleven ESR proposals in 2002-3. Five of those ESR proposals have been approved and four proposals have been approved after some revisions. Two proposals deferred but not resumed.

The reasons for asking to revise the study protocols include; incomplete documentation, concern about socio-cultural issues, legal issues and concern about placebo controls. Approval from the national ethics committee is not a necessary requirement for ESR proposals to be conducted in Japan and the local ethics committee can make a decision independently. Asking who is responsible to review whether ESR proposal is conforms with scientific principles half of them replied that ECs should decide and no need to send the proposal to the scientific committee.

As shown in Table 4, out of nine approved ESR projects, eight proposals were as bilateral collaborations, and one as a multinational collaboration. In five cases the role of Japanese collaborators simply was to collect the samples. There was one multinational project which data were analyzed in country in origin. In 7 cases the data have been analyzed in Japan.

Their answers to the question about the character of funding agencies were not clear. The host collaborator in 5 cases were researchers and in other cases Japanese Universities were as collaborators.

Discussion

The research approval responsibility lies with the researchers as well as the ethics committee, no matter, if a study protocol is submitted by a local institute or suggested from a foreign collaborator.

Lessons from the experience of AZT trials in Africa and Asia in 1990s [6] warned health policy makers to take enough measures to ensure post trial access for the local community. Although there is a general consensus that participants should benefit from taking part in research.[7]. Who should supply post-trial treatment, and how? This issue has caused controversies in the area of ethics in research. In a note of clarification on paragraph 30 of the declaration of Helsinki (2000), the World Medical Association (WMA) gives the responsibility to ethics review committee to ensure that post-trial access is described to the study protocol [8].

It has been stressed by international guidelines that researchers should endeavor to secure post-trial access to effective interventions for all the participants in a trial who could benefit [9]. This issue did not get enough attention of the ethics committees in Japan, as only two ECs out of eleven, expressed their strong concern. Whether it is because Japan is an industrial country and such issue does not make them worry is open to question.

How ethics committee approach the issue of risk/benefit assessment is critical. If the ethics committees give more weight to "more benefits" in their risk/benefit assessment, and take "more benefits" as the standard of their assessment, then exposure of the subjects to a high-risk situation under the pretext of more benefits for the society and even for the subjects themselves could be argued. This condition may gain significance especially in such research as vaccine trials in developing countries. However, if the committees gives more weight to the degree of risks inflicted on the subjects in this assessment, that is, if they take the amount of "risks inflicted on the subjects" as their standard, then they will do their best to protect the subjects against impending risks and search for strategies to lessen the degree of risks or even search for alternative methods [10].

This survey shows that Japanese ECs gave more priority to "avoiding harm to the subjects" rather than benefits to the society in their risk/benefit assessment.

Research in developing countries was a flash point behind the fifth revision of Helsinki because the declaration retains the requirement that new treatments should be tested against the "best current" treatment [11]. It worthwhile to mention the Nuffield Council on Bioethics position in this regard "wherever appropriate, participants in the control group should be offered a "universal standard of care" for the disease being studied".

In our survey, international standard has been given more attention than local standards as the "standard of care" by Japanese ECs.

Conclusion

Ethics in research especially dealing with externally-sponsored research is relatively a new subject and under developing in Japan. Although Japan is not a developing country, in order to protect individual human subjects and local community still capacity building in ethics review especially in research collaboration with other developed and developing countries is crucial and it has to be included in ethics in research program through out the country.

On the other hand, if Japanese researchers want to carry out research in less powerful nations, ethically sound research requires them to be familiar with ethical issues arise in ESR project in host country and to be aware of socio-cultural sensitivities in host country.

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Bioethics in Africa: The new human genetics and a case for responsible global governance

- Merry Osemwegie, Ph.D.
128 Woodbrook Rd, London England SE2 0PA
Email: Merry.Osemwegie@btinternet.com

Introduction

The on-going developments in human genetics highlight a number of realistic possibilities such as the ability not only to identify and to treat many 1ch the basis of public opinion that we are able to gauge public receptivity towards the possibilities raised by the new human genetics (Brown 2003b).

Methods and sample

To gauge attitudes of university students towards libertarian eugenics in developed and developing countries, two questionnaire surveys were conducted. One survey was carried out at the University of Benin (Nigeria) and the other at the University of Manchester (England). The questions were framed to look at how the respondents would receive the possibilities raised by the new genetics given that the means and techniques were safe and available. The questions were thoroughly thought through and were designed specifically rather than adopted. The temptation to simply use questions that have been used in previous surveys was highly resisted to ensure that the issues in the questions were tailored to the specific context (Reiss & Straughan 1996).

The survey questionnaire explores general knowledge about genetic engineering and trends of libertarian eugenics, for example, sex selection, termination of embryos on the basis of disability, health and non-health related enhancement, cloning and regulation (see tables). There were 39 questions in total, which the respondents were asked to answer using pre-set options: 'yes, more likely to agree, less likely to agree, no, undecided'. The questionnaire contained a brief explanatory note. Each question allowed for 'any other comment' and there was a separate provision for 'general comments' at the end of the questionnaire. Some questions were preceded by case-scenarios (see Q9). There were, where necessary, some brief explanations of some of the terminology as applied to the context in which specific questions were asked. For practical reasons, the questionnaire was piloted in the UK only. Samples were drawn from a cross section of both postgraduate and undergraduate students from different academic disciplines to reflect diverse views of, for example, law, economics and political science, although it was not specifically 'discipline-led'.

In Nigeria, 710 students were asked to complete the questionnaire compared with 390 students in Manchester. The questionnaires were generally distributed and collected within 40 minutes with the cooperation of the university lecturers and fellow students. The survey sample, as with other attitude surveys, cannot represent per se the opinion of the entire population of African and British university students. Yet the student sample and the findings, it could be argued, represent the opinion of a sizeable academic group. The age group was unrestricted but categorised (see question 1)

Useful observations on the nature of the survey

Undoubtedly, a survey of this kind is subject to bias and preconceived ideas that may shape the analysis because of

limited choice (Macer et al 1995), especially when provisions are not made for comments and/or 'other choice'. There is another problematic issue. This relates to 'on the spot completion' of questionnaires: perhaps given more time, the respondents would have thought and reflected on the choices to be made and perhaps would have changed their minds. This is because opinions and choices may change over time and abstract choices may be easier than in practice (Wert 2000; Straughan 1989). It is worth noting, however, that the respondents were asked to try to be as honest as possible in their choice of answers. Meanwhile, many of these difficulties may have been avoided by the simple and concise ways in which the questions were phrased just as some detailed breakdown of specific issues was provided which, in turn generated specific responses (Macer 1995). The data, it is hoped, would provide some significant pointers particularly regarding how the developments and policies in the North may affect others in distant territories in the South and how these interconnected issues may be embedded in a global context.

There is the problem commonly associated with social research. That is, of selecting and prioritising what areas to analyse because of so many connected social issues that may invite correlations. There is what may be seen as a biased analysis in terms of what is deemed to be worthy of notice. The biased analysis can be seen when the focus is on those who said yes rather those who said no. It must be reiterated that one of the aims of the survey is to assess how the respondents would receive the new eugenics and whether an increased eugenic tendency justifies the need for regulation; thus the emphasis may be biased towards how many respondents said 'Yes' to the idea of creating genetic copies of themselves (15% and 2%) as against the de-emphasis on the 88% and 60% who said 'No' (Q25a – table 4.3).

I have deliberately avoided the temptation to correlate my findings unnecessarily and to compare my findings with previous surveys because the questions were not exactly identical. Other survey findings, however, are referred to when they become unavoidably necessary. Hypothetically, the questions were asked on the basis of an assumption that the gene-techniques were safe and available to use by respondents at the crucial time of prenatal testing and at the initial stages of embryo development. A number of deductions could be made on the basis of the extra comments and suggestions made by respondents. However, as the research is, in the main, quantitative rather than qualitative, the deductions and additional comments made by respondents do not form major parts of the analysis and some comments are made available in the appendix.

As noted above, there is every temptation to engage in endless analyses in the two comparative surveys. It is worth noting that the principle aim of the survey was neither to look at attitudes of women towards sex selection nor how gender shapes the idea of cloning or how the age of the respondents would affect their choices or how these attitudes correlate with other issues raised in the survey. This is not to suggest that these correlations are to be ignored because they may help to shed broader light on many issues. For example, if it were the case that the respondents under the age of 19 revealed a marked preference for sex selection (Q9), then these preferences would raise issues of a different kind. I looked however at, for example, the correlations between gender and the decision to increase the IQ of our children or to engage in termination of defective embryos. Here, there was no significant pattern by gender.

It was considered pointless to simply 'explain what is obvious' from the tables as this would amount to repetition of the obvious facts even though it is recognised that obvious facts are what survey data are meant to convey. It is useful

to shed light on the factors that may have influenced respondents' attitudes, for example, whether or not cultural tradition or religion (e.g. being evangelical) would have some bearing on whether to accept or delete a gene responsible for homosexuality (see Q15 & 16). Thus, in a comparative survey like this, it becomes inevitable and important to explain any remarkable differences in the answers provided by the respondents in Africa and Manchester and the reason/s why this is the case. The main focus, however, in terms of relevance to this thesis is the ultimate answer yes or no etc while the factors that influence the choices made remain secondary. Further surveys are needed to provide detailed analysis of how these factors underpin attitudes towards eugenics.

Empirical evidence and useful observations

There are significant similarities and significant differences in the attitudes of respondents from Manchester and Africa. Where there are similarities, e.g. on regulation, these similarities, on one level, would support the call for a common approach to redress any potential misgivings by way of a global bioethics framework. From another level, significant differences in terms of negative attitudes towards disability would support the need for a global bioethics framework if, for example, the potentially defective newborn in Africa appears to have less chance of survival or of being born at all due to less tolerance towards human diversity amidst the absence of current policies to address these potential misgivings on local or regional level.

Awareness of new human genetics

There appears to be a similarly low level of awareness of human genetics, genetic engineering and genetic discrimination in insurance and employment. However, 18% of the respondents in Africa have never heard of genetic engineering as against 0% in Manchester (Q6 – table 1.2). The data also show that 37% were very much aware of genetic discrimination in employment and insurance in Africa as against 15% in Manchester even though there is no evidence to suggest wide practices in the former (Q24b – table 4.1). Secondary school students in Africa, however, according to Hayes (2004), rely on popular mass media, for example, newspapers and television (where these are available) for their information about developments in biotechnology. Whilst this could easily be assumed in relation to university students, the use of university reference library and electronic technology may well account for the awareness. It would be an understatement to say that media coverage help to shape policies and public attitudes towards the new genetics in the West (Nelkin 2000).

Attitudes towards genetic deformities and otherness

A significant proportion of the respondents support the need to design our children to correct genetic deformities (e.g. sickle cell anaemia and cystic fibrosis) 43% in Manchester and 65% in Africa, and yet 11% and 13% would decline to correct these deformities (Q11a – table 1.8). The same attitudes are reflected in the marked differences in the attitudes towards others who are different. Negative attitudes towards sexual orientation were clearly visible among respondents in Africa with 59% ready to delete a gay gene if the gene would make their babies become homosexuals as against 12% in Manchester. The same pattern is seen in the attitudes towards lesbianism with 57% in Africa willing to delete a lesbian gene as against 11% in Manchester (Q15a & b – tables 3.0 & 3.1).

The same negative attitudes are revealed towards disabilities where 39% would terminate pregnancy among the African

respondents on the basis of severe disability as against 16% in Manchester (Q20a – table 3.5). Equally, a higher proportion of the respondents in Africa (20%) would terminate pregnancy on the basis of minor deformity as against 4% in Manchester (Q20b – table 3.6). The same negative attitudes are shown in the event of an increasing number of people with genetic diseases, with 28% of the African respondents saying they would resist the proliferation of the disabled group whilst 11% of the respondents in Manchester would use the increase in numbers of disabled people to justify the prevention of disabled people from reproducing (Q23 – table 3.9).

In another survey conducted earlier in China – another developing country - 89% would carry out abortion of deformed babies whilst 85% would do so if there were a 5% chance of genetic risk (Macer 1994). Lo et al (1994) report that 34% would delete defective embryos if the chance of genetic defect were 1% and that a majority of the respondents in higher education were in support of eugenics in China with 72% willing to abort in the event of serious genetic defects whilst 87% would do so in the case of Down's Syndrome. However, a December (2002) report in America shows that two thirds of respondents approved of genetic engineering to cure serious genetic defects whilst 70% rejected engineering for social reasons. An earlier report has also shown that 9 out of 10 agreed with genetic engineering to cure genetic diseases (MORI 2001). Elmer-Dewith's (1994) survey shows that 79% of the respondents agreed that genetic engineering should be used to cure diseases as against 16% who disagreed. March of Dimes (1992) reports too that 78% and 87% agreed to use genetic engineering to reduce risk or cure fatal diseases respectively.

Influences on genetic engineering

That our cultural background influences our choice is noted equally in both Africa and Manchester in the case of sex selection with 26% and 21% answering yes whilst 32% and 42% said no respectively (Q10 – table 1.7). Scofield (2000) also reports that 80% of the respondents would reject pre-sex selection of a foetus and 74% would not change the physical make up of their children either. This is equally the case in relation to whether culture would have an influence on the decision to design a perfect baby. Here too there is a close range - 20% and 22% answered yes in Manchester and Africa with corresponding 46% and 43% saying no respectively (Q13 – table 2.3). A similar range is seen in relation to whether respondents would engage in genetic engineering even if the means to do so were not equally available to everyone. Thus a high proportion of respondents from Africa (49%) and 46% from Manchester would go ahead nonetheless (14c – table 2.6). Free access to the means of engineering influenced more respondents from African (30%) than those from Manchester (8%) with 35% and 57% refusing to design irrespective of whether or not genetic engineering was free (Q12 – table 2.2). It would appear that what other people do does have some influence on our decision to design. This is shown by the fact that among the respondents who refused to design their perfect babies 18% in Africa would change their mind as against 6% from Manchester if they observe that people who designed their babies were obviously benefiting (Q14b – table 2.5).

Results Tables

Note: The 'Mann-Whitney Test' statistical technique was used to test whether there was any significant difference between the two groups from Africa and Manchester.

Table 0.1 Question 1: Age group

Manchester Q1			Africa Q1			
	Frequency	Percent		Frequency	Percent	
Under 18	24	6.2		Under 18	19	2.7
19-39	363	93.1		19-39	658	92.8
40-65	2	.5		40-65	21	3.0
Over 65	1	.3		Over 65	6	.8
<u>Total</u>	390	100.0		Valid missing	5	.6
				<u>Total</u>	709	100.0

Asymp. Sign. (P<0.0005)

Table 0.2 Question 2: How would you describe yourself?

Manchester Q2			Africa Q2			
	Frequency	Percent		Frequency	Percent	
White	291	74.6		White	22	3.1
Black	17	4.4		Black	642	90.1
Mixed race	12	3.1		Mixed race	22	3.1
Asian	60	15.4		Asian	5	.7
Other	8	2.1		Other	10	1.4
Missing system	2	.5		Valid missing	8	1.1
<u>Total</u>	390	100.0		<u>Total</u>	709	100.0

Asymp. Sign. (P<0.0005)

Table 0.3 Question 3: Gender

Manchester Q3			Africa Q3			
	Frequency	Percent		Frequency	Percent	
Female	203	52.1		Female	269	37.9
Male	187	47.9		Male	439	61.9
<u>Total</u>	390	100.0		Valid missing	1	.1
				<u>Total</u>	709	100.0

Asymp. Sign. (P<0.0005)

Table 0.4 Question 4: Are you disabled?

Manchester Q4			Africa Q4			
	Frequency	Percent		Frequency	Percent	
Yes	5	1.3		Yes	20	2.8
No	384	98.5		No	679	95.8
Missing system	1	.3		Valid missing	10	1.4
<u>Total</u>	390	100.0		<u>Total</u>	709	100.0

Asymp. Sign. (P< 0.013)

Questions 5-6: Comparative opinion on knowledge of human genetics and genetic engineering

Table 1.1 question 5: Have you ever been informed by health professionals (your GP, counsellor or Nurse) about developments in human genetics?

Manchester Q5			Africa Q5			
	Frequency	Percent		Frequency	Percent	
Yes	25	6.4		Yes	242	34.1
No	359	92.1		No	400	56.4
Undecided	6	1.5		Undecided	40	5.6
<u>Total</u>	390	100.0		Valid missing	27	3.8
				<u>Total</u>	709	100.0

Asymp. Sign. (P<0.0005)

Table 1.2 Question 6: How much do you know about genetic engineering?

Manchester Q6			Africa Q6			
	Frequency	Percent		Frequency	Percent	
Very much	17	4.4		Very much	44	6.2
Somewhat aware	207	53.1		Somewhat aware	138	19.5
Little awareness	164	42.1		Little awareness	364	51.3
Never heard of it	0	0		Never heard of it	128	18.1
Undecided	2	.5		Undecided	17	2.4
<u>Total</u>	390	100.0		Valid missing	18	2.5
				<u>Total</u>	709	100.0

Asymp. Sign. (P< 0.0005)

Questions 7: Comparative opinion on genetic enhancement for non-health related purposes – via genetic therapy and non-gene therapeutic means

Table 1.3 question 7a: *Do you think that free genetic screening for the purpose of identifying and treating genetic diseases is a good thing?*

Manchester Q7a			Africa Q7a		
	Frequency	Percent		Frequency	Percent
Yes	300	76.9	Yes	545	76.9
No	21	5.4	No	54	7.6
Undecided	68	17.4	Undecided	81	11.4
Valid missing	1	.3	Valid missing	29	4.1
Total	390	100.0	Total	709	100.0

Asymp. Sign. (P<0.006)

Table 1.4 Question 7b: *Do you think that human genetic engineering to enhance non-health related traits (e.g. colour, IQ, height etc) should be allowed?*

Manchester Q7b			Africa Q7b		
	Frequency	Percent		Frequency	Percent
Yes	17	4.4	Yes	186	26.2
More likely to	20	5.1	More likely to	89	12.6
Less likely to	82	21.0	Less likely to	87	12.3
No	255	65.4	No	236	33.3
Undecided	16	4.1	Undecided	72	10.2
Total	390	100.0	Valid missing	39	5.5
			Total	709	100.0

Asymp.Sign. (P<0.0005)

Questions 9-10: Comparative opinion on sex selection and influences on decisions

Table 1.5 Q8: *If you could influence the appearance and behaviour of your child by means of vitamin supplements would you do so?*

Manchester Q8			Africa Q8		
	Frequency	Percent		Frequency	Percent
Yes	97	24.9	Yes	437	61.6
More likely to	117	30.0	More likely to	86	12.1
Less likely to	60	15.4	Less likely to	53	7.5
No	85	21.8	No	92	13.0
Undecided	31	7.9	Undecided	27	3.8
Total	390	100.0	Valid missing	14	2.0
			Total	709	100.0

Asymp.Sign. (P<0.0005)

Table 1.6 Q9: *"Of course I knew that Max would be a boy. My husband and I chose him from the embryo we made. And when I am ready to go through this again, I will choose a girl to be my second child. An older son and a young daughter - a perfect family" If you were in the above situation, would you select the sex of your baby to ensure that a son is your preferred first choice?*

Manchester Q9			Africa Q9		
	Frequency	Percent		Frequency	Percent
Yes	16	4.1	Yes	287	40.5
More likely to	25	6.4	More likely to	69	9.7
Less likely to	35	9.0	Less likely to	66	9.3
No	302	77.4	No	231	32.6
Undecided	11	2.8	Undecided	44	6.2
Valid missing	1	.3	Valid missing	12	1.7
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.0005)

Table 1.7 Q10: *Do you think that your cultural background would influence your decision to select the sex of your child?*

Manchester Q10			Africa Q10		
	Frequency	Percent		Frequency	Percent
Yes	85	21.8	Yes	190	26.8
More likely to	66	16.9	More likely to	120	16.9
Less likely to	61	15.6	Less likely to	140	19.7
No	166	42.6	No	233	32.9
Undecided	10	2.6	Undecided	13	1.8
Missing	2	.5	Missing	13	1.8
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.001)

Question 11: Comparative opinion on genetic engineering for health reasons

Table 1.8 Q11a: *If you had the opportunity, and the techniques were perfectly safe, would you want to design your children in order to avoid genetic diseases? (Design here means, for the purpose of health related improvement – cystic fibrosis, sickle cell anaemia etc.)*

Manchester Q11a			Africa Q11a		
	Frequency	Percent		Frequency	Percent
Yes	170	43.6	Yes	461	65.0
More likely to	118	30.3	More likely to	83	11.7
Less likely to	18	4.6	Less likely to	34	4.8
No	52	13.3	No	84	11.8
Undecided	30	7.7	Undecided	37	5.2
Valid missing	1	.3	Valid missing	10	1.4
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.0005)

Table 1.9 Q11b: *Would you want to design your children? (Design here means, for the purpose of non-health related enhancement that would conform to your preferred height, colour, IQ etc)*

Manchester Q11b			Africa Q11b		
	Frequency	Percent		Frequency	Percent
Yes	11	2.8	Yes	209	29.5
More likely to	24	6.2	More likely to	97	13.7
Less likely to	39	10.0	Less likely to	78	11.0
No	300	76.9	No	271	38.2
Undecided	16	4.1	Undecided	42	5.9
Total	390	100.0	Valid missing	12	1.7
			Total	709	100.0

Asymp.Sign. (P<0.0005)

Table 2.0 Q11c: *If your answer to Question 11b above was either [yes], [more likely] or [less likely], would you want the new characteristics of your designed baby to be transferred to your grandchildren?*

Manchester Q11c			Africa Q11c		
	Frequency	Percent		Frequency	Percent
Yes	25	6.4	Yes	241	34.0
No	35	9.0	No	129	18.2
Not sure	44	11.3	Not sure	103	14.5
Valid missing	286	73.3	Missing system	1	.1
Total	390	100.0	Valid missing	235	33.1
			Total	709	100.0

Asymp.Sign. (P<0.0005)

Table 2.1 Q11d: *If your answer to Question 11b above was either [No] or [undecided], would you design your own baby if the majority of the population were doing so?*

Manchester Q11d			Africa Q11d		
	Frequency	Percent		Frequency	Percent
Yes	18	4.6	Yes	60	8.5
More likely to	76	19.5	More likely to	50	7.1
Less likely to	32	8.2	Less likely to	36	5.1
No	188	48.2	No	267	37.7
Undecided	26	6.7	Undecided	33	4.7
Missing system	12	3.1	Missing system	1	.1
Valid missing	38	9.7	Valid missing	262	37.0
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.0005)

Table 2.2 Q12: *If genetic engineering were free, would this influence your decision to design your own perfect baby? (Design here means to design for health and non-health related purposes) (Perfect here means your own idea of perfection)*

Manchester Q12			Africa Q12		
	Frequency	Percent		Frequency	Percent
Yes	33	8.5	Yes	213	30.0
More likely to	76	19.5	More likely to	107	15.1
Less likely to	34	8.7	Less likely to	64	9.0
No	224	57.4	No	250	35.3
Undecided	23	5.9	Undecided	51	7.2
Total	390	100.0	Missing system	1	.1
			Valid missing	23	3.2
			Total	709	100.0

Asymp.Sign. (P<0.0005)

Question 13: Comparative opinion on influences on decisions on health and non-health improvement

Table 2.3 Q13: *Do you think that your cultural background would influence your decision to design your own perfect baby? (Design here means to design for health and non-health related purposes)*

Manchester Q13			Africa Q13		
	Frequency	Percent		Frequency	Percent
Yes	81	20.8	Yes	162	22.8
More likely to	61	15.6	More likely to	85	12.0
Less likely to	39	10.0	Less likely to	84	11.8
No	183	46.9	No	311	43.9
Undecided	23	5.9	Undecided	41	5.8
Valid missing	3	.8	Valid missing	26	3.7
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.166)

Questions 14a-14c: Comparative opinions on IQ enhancement

Table 2.4 Q14a: *"I just wanted to make sure that Max would have the greatest chance for achieving success. Having low intelligence, a particular colour or being disabled or short height would clearly be a handicap" Imagine you were in this situation and that a safe technique and reliable prenatal test were available to increase your child's intelligence (IQ), would you use it?*

Manchester Q14a			Africa Q14a		
	Frequency	Percent		Frequency	Percent
Yes	45	11.5	Yes	360	50.8
More likely to	62	15.9	More likely to	110	15.5
Less likely to	45	11.5	Less likely to	62	8.7
No	201	51.5	No	122	17.2
Undecided	37	9.5	Undecided	32	4.5
Valid missing			Valid missing	23	3.2
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.0005)

Table 2.5 Q14b: *If your answer to question 14a was either [less likely], [no] or [undecided], would you increase your child's IQ if people around you were doing this and were obviously at advantage?*

Manchester Q14b			Africa Q14b		
	Frequency	Percent		Frequency	Percent
Yes	24	6.2	Yes	130	18.3
More likely to	99	25.4	More likely to	50	7.1
Less likely to	27	6.9	Less likely to	40	5.6
No	95	24.4	No	129	18.2
Undecided	34	8.7	Undecided	37	5.2
Valid missing	111	28.5	Valid missing	323	45.6
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.0005)

Table 2.6 Q14c: *If the means to increase a child's IQ were not available equally to everyone, would this influence your decision not to increase your child's IQ?*

Manchester Q14c			Africa Q14c		
	Frequency	Percent		Frequency	Percent
Yes	104	26.7	Yes	117	16.5
More likely to	55	14.1	More likely to	66	9.3
Less likely to	24	6.2	Less likely to	69	9.7
No	180	46.2	No	348	49.1
Undecided	23	5.9	Undecided	67	9.4
Valid missing	4	.8	Valid missing	42	5.9
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.030)

Questions 14d-14e: Comparative opinions on height and colour engineering

Table 2.7 Q14d: *Imagine that you were in the above situation (14a), would you want to improve the height of your child by ensuring that he/she grows up to be at least 6ft tall?*

Manchester Q14d			Africa Q14d		
	Frequency	Percent		Frequency	Percent
Yes	17	4.4	Yes	206	29.1
More likely to	19	4.9	More likely to	96	13.5
Less likely to	35	9.0	Less likely to	101	14.2
No	300	76.9	No	232	32.7
Undecided	18	4.6	Undecided	41	5.8
Valid missing	1	.3	Valid missing	33	4.7
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.0005)

Table 2.8 Q14e: *Imagine that you were in the above situation (14a), would you adjust a gene responsible for your child's skin colour? In your answer please indicate, where possible, what factor/s influenced your decision*

Manchester Q14e			Africa Q14e		
	Frequency	Percent		Frequency	Percent
Yes	3	.8	Yes	80	11.3
More likely to	7	1.8	More likely to	50	7.1
Less likely to	14	3.6	Less likely to	77	10.9
No	357	91.5	No	404	57.0
Undecided	8	2.1	Undecided	42	5.9
Valid missing	1	.3	Valid missing	56	7.9
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.0005)

Questions 15a-15b: Comparative attitudes to gay and lesbianism

Table 2.9 Q15a: *Imagine that some reliable prenatal tests have shown that your male child has a particular gene that would be responsible for his homosexuality, (gay's sexuality) if it were possible would you delete this gene? In your answer please indicate, where possible, what factor/s influenced your decision.*

Manchester Q15a			Africa Q15a		
	Frequency	Percent		Frequency	Percent
Yes	48	12.3	Yes	418	59.0
More likely to	31	7.9	More likely to	65	9.2
Less likely to	24	6.2	Less likely to	34	4.8
No	259	66.4	No	105	14.8
Undecided	27	6.9	Undecided	48	6.8
Valid missing	1	.3	Valid missing	39	5.5
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.0005)

Table 3.0 Q15b: *Imagine that some reliable prenatal tests have shown that your female child has a particular gene that would be responsible for her homosexuality, (lesbianism) if it were possible would you delete this gene? In your answer please indicate, where possible, what factor/s influenced your decision*

Manchester Q15b			Africa Q15b		
	Frequency	Percent		Frequency	Percent
Yes	45	11.5	Yes	409	57.7
More likely to	28	7.2	More likely to	65	9.2
Less likely to	25	6.4	Less likely to	41	5.8
No	262	67.2	No	104	14.7
Undecided	29	7.4	Undecided	47	6.6
Valid missing	1	.3	Valid missing	43	6.1
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.0005)

Question 16: Comparative attitudes towards discrimination

Table 3.1 Q16: *If tests showed that a gene was responsible for our tendency to discriminate against one another, would you want to remove the gene if possible?*

Manchester Q16			Africa Q16		
	Frequency	Percent		Frequency	Percent
Yes	72	18.5	Yes	354	49.9
More likely to	94	24.1	More likely to	88	12.4
Less likely to	30	7.7	Less likely to	72	10.2
No	152	39.0	No	109	15.4
Undecided	39	10.0	Undecided	44	6.2
Missing system	1	.3	Missing system	1	.1
Valid missing	2	.5	Valid missing	41	5.8
Total	390	100.0	Total	709	709

Asymp. Sign. (P<0.0005)

Question 17: Comparative opinions on regulation

Table 3.2 Q17: *Imagine that there is now a growing freedom for people to design their children, would you agree that such reproductive freedom should be regulated? (Design here means to design for health and non-health related purposes)*

Manchester Q17			Africa Q17		
	Frequency	Percent		Frequency	Percent
Yes	268	68.7	Yes	313	44.1
More likely to	45	11.5	More likely to	85	12.0
Less likely to	17	4.4	Less likely to	50	7.1
No	43	11.0	No	179	25.2
Undecided	17	4.4	Undecided	48	6.8
Total	390	100.0	Valid missing	34	4.8
			Total	709	100.0

Asymp.Sign. (P<0.0005)

Question 18: Comparative opinion on genetic engineering: whose interest?

Table 3.3 Q18: Following question 17 above, would you say that this reproductive freedom to design a baby is for the best interest of the child?

Manchester Q18			Africa Q18		
	Frequency	Percent		Frequency	Percent
Yes	33	8.5	Yes	194	27.4
More likely to	55	14.1	More likely to	107	15.1
Less likely to	52	13.3	Less likely to	70	9.9
No	199	51.0	No	237	33.4
Undecided	51	13.1	Undecided	64	9.0
Total	390	100.0	Valid missing	37	5.2
			Total	709	100.0

Asymp. Sign. (P<0.0005)

Question 19: Comparative opinion on reservations on genetic engineering

Table 3.4 Q19: What reservation, if any, do you have about human genetic engineering? (Genetic engineering here means designing human genes both for health improvement and non-health related purposes) (You may choose more than one option)

Manchester Q19			Africa Q19		
	Frequency	Percent		Frequency	Per.
Playing God	68	17.4	Playing God	135	19.0
Playing with nature	105	26.9	Playing with nature	153	21.6
Uncertainty	35	9.0	Uncertainty	57	8.0
Undecided	9	2.3	Undecided	82	11.6
None	4	1.0	None	18	2.5
Valid missing	169	43.3	Valid missing	264	37.2
Total	390	100.0	Total	709	100.0

Asymp. Sign. (P< 0.003)

Questions 20a-20b: Comparative attitudes to severe and minor disability

Table 3.5 Q20a: Imagine there was a genetic defect following a pre-natal test, would you terminate the pregnancy if the disorder were considered by physicians to be a severe disability? (Severity here means learning difficulty, needing extra education, having lung and digestive problems and in need of daily treatment and likely to die before adulthood)

Manchester Q20a			Africa Q20a		
	Frequency	Percent		Frequency	Percent
Yes	65	16.7	Yes	277	39.1
More likely to	123	31.5	More likely to	76	10.7
Less likely to	33	8.5	Less likely to	53	7.5
No	77	19.7	No	160	22.6
Undecided	88	22.6	Undecided	99	14.0
Valid missing	4	1.0	Valid missing	44	6.2
Total	390	100.0	Total	709	100.0

Asymp. Sign. (P<0.0005)

Table 3.6 Q20b: Imagine there was a genetic defect following a pre-natal test, would you terminate the pregnancy if the disorder were considered by physicians to be a minor disability? (Minor deformity here means a non-life threatening deformity but which may hinder to some degree the full fulfilment of life and life aspirations)

Manchester Q20b			Africa Q20b		
	Frequency	Percent		Frequency	Percent
Yes	17	4.4	Yes	148	20.9
More likely to	28	7.2	More likely to	83	11.7
Less likely to	106	27.2	Less likely to	107	15.1
No	208	53.3	No	255	36.0
Undecided	28	7.2	Undecided	68	9.6
Missing system	3	.8	Valid missing	48	6.8
Total	390	100.0	Total	709	100.0

Asymp. Sign. (P<0.0005)

Questions 21-23: Comparative attitudes to caring for and increasing the number of the genetically disadvantaged group

Table 3.7 Q21: Caring for the less privileged people is justified by 'our moral responsibility to care for others' whether or not it is a huge burden on the welfare system or the state's economy. This is a position I would support.

Manchester Q21			Africa Q21		
	Frequency	Percent		Frequency	Percent
Yes	228	58.5	Yes	490	69.1
More likely to	111	28.5	More likely to	98	13.8
Less likely to	18	4.6	Less likely to	29	4.1
No	13	3.3	No	29	4.1
Undecided	18	4.6	Undecided	25	3.5
Valid missing	2	.5	Valid missing	38	5.4
Total	390	100.0	Total	709	100.0

Asymp. Sign (P<0.0005)

Table 3.8 Q22: In relation to Q21 above, you are told that the yearly costs to the government for one particular genetic disease alone is about £200,000 per person, would this change your views?

Manchester Q22			Africa Q22		
	Frequency	Percent		Frequency	Percent
Yes	17	4.4	Yes	78	11.0
More likely to	32	8.2	More likely to	55	7.8
Less likely to	40	10.3	Less likely to	92	13.0
No	259	66.4	No	378	53.3
Undecided	40	10.3	Undecided	58	8.2
Valid missing	2	.5	Valid missing	48	6.8
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.0005)

Table 3.9 Q23: Assuming there was an increase in the number of people with genetic diseases. Do you think that this increase justifies society to prevent the 'defective' group from reproducing?

Manchester Q23			Africa Q23		
	Frequency	Percent		Frequency	Percent
Yes	43	11.0	Yes	203	28.6
No	248	63.6	No	294	41.5
Undecided	94	24.1	Undecided	152	21.4
Valid missing	4	.8	Valid missing	60	8.5
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P< 0.0005)

Questions 24b-24c: Comparative attitudes towards informed consent and genetic discrimination

Table 4.0 Q24a: Would you agree that a third party, without your consent, should share genetic information revealed during your medical examination?

Manchester Q24a			Africa Q24a		
	Frequency	Percent		Frequency	Percent
Yes	8	2.1	Yes	89	12.6
More likely to	9	2.3	More likely to	32	4.5
Less likely to	21	5.4	Less likely to	65	9.2
No	331	84.9	No	435	61.4
Undecided	21	5.4	Undecided	44	6.2
Valid missing			Valid missing	44	6.2
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.0005)

Table 4.1 Q24b: Are you aware that it is possible for some employers or insurance companies to use your genetic information to discriminate against you and your family?

Manchester Q24b			Africa Q24b		
	Frequency	Percent		Frequency	Percent
Very much aware	59	15.1	Very much	265	37.4
Somewhat aware	87	22.3	Somewhat aware	101	14.2
Little awareness	94	24.1	Little awareness	85	12.0
Never heard of it	148	37.9	Never heard of it	183	25.8
Undecided	2	.5	Undecided	35	4.9
Valid missing			Valid missing	40	5.6
Total	390	100.0	Total	709	100.0

Asymp. Sign. (P< 0.0005)

Table 4.2 Q24c: Imagine that there were evidence to indicate discriminatory practices in 24b above would such practice prevent you from taking part in future genetic screening for yourself or pre-natal test for your child?

Manchester Q24c			Africa Q24c		
	Frequency	Percent		Frequency	Percent
Yes	86	22.1	Yes	140	19.7
More likely to	109	27.9	More likely to	73	10.3
Less likely to	39	10.0	Less likely to	88	12.4
No	83	21.3	No	275	38.8
Undecided	67	17.2	Undecided	72	10.2
Valid missing	6	1.5	Valid missing	61	8.6
Total	390	100.0	Total	709	100.0

Asymp.Sign. (P<0.943)

Questions 25a & b: Comparative attitudes towards human cloning

Table 4.3 Q25a: "Why the fuss about clones? There are many identical twins everywhere living their own separate lives. They are never the same" Assuming cloning means creating a living genetic copy of yourself: if it were possible, would you clone yourself?

Manchester Q25a			Africa Q25a		
	Frequency	Percent		Frequency	Percent
Yes	11	2.8	Yes	112	15.8
More likely to	7	1.8	More likely to	41	5.8
Less likely to	17	4.4	Less likely to	42	5.9
No	345	88.5	No	427	60.2
Undecided	10	2.6	Undecided	51	7.2
Total	390	100.0	Valid missing	36	5.1
			Total	709	100.0

Asymp.Sign. (P<0.0005)

Table 4.4 Q25b: If it were possible to adjust your clone in 25a above, would you want to remove from the clone habits that you considered to be bad? (If your answer to 25a was [no] could you please answer 25b however assuming that your clone was made)

Manchester Q25b			Africa Q25b		
	Frequency	Percent		Frequency	Percent
Yes	43	11.0	Yes	215	30.3
More likely to	52	13.3	More likely to	81	11.4
Less likely to	27	6.9	Less likely to	44	6.2
No	213	54.6	No	143	20.2
Undecided	36	9.2	Undecided	103	14.5
Valid missing	19	4.9	Valid missing	123	17.3
Total	390	100.0	Total	709	100.0

Asymp. Sign. (P<0.0005)

Question 26: Comparative attitudes towards regulation

Table 4.5 Q26: Please answer the following question only if you answered "Yes" or "More likely" to one or more of the questions about engineering. If the kind of engineering you would want is prohibited in your country, would you then be prepared to go to another country to have it done?

Manchester Q26			Africa Q26		
	Frequency	Percent		Frequency	Percent
Yes	29	7.4	Yes	173	24.4
More likely to	35	9.0	More likely to	101	14.2
Less likely to	19	4.9	Less likely to	73	10.3
No	93	23.8	No	134	18.9
Undecided	22	5.6	Undecided	49	6.9
Valid missing	192	49.2	Valid missing	179	25.2
Total	390	100.0	Total	709	100.0

Asymp. Sign. (P<0.0005)

Attitudes towards improving the characteristics of our babies

To the question whether the respondents would design their babies in general (Q11b – table 1.9), a significantly higher proportion of respondents in Africa said they would do so (29%) as against 2% in Manchester. Similar results were found in the case of attitudes towards improving the qualities of our babies via the use of vitamins (Q8 - table 1.5) where 24% and 61% respondents answered yes in Manchester and Africa respectively. This seems to reflect the result of an earlier report in England where the respondents were up to 4 times as likely to use vitamins to improve the characteristics of their babies as against using genetic intervention (Marteau et al 1995). There is also a marked disparity in terms of how respondents see low IQ as a socio-economic handicap. In Africa, a significantly higher proportion of respondents (50%) would increase the IQ of their babies as against 11% in Manchester (14a – table 2.4). These figures from a developing country can be compared with reports from a previous survey conducted in America by Time/CNN where 34% would improve the IQ level of their children as against 62% who would not do so (Elmer-Dewith 1994). Two years earlier, March of Dimes (1992) reported also that 42% agreed with IQ enhancement as against 55% who disagreed. In an

earlier survey conducted by the American's OTA (1986), 53% of the respondents disapproved of IQ enhancement whilst 44% were in favour.

Interestingly, there is a dissimilar response to the question of whether engineering to enhance non-health related traits should be allowed; with 4% and 26% saying yes in Manchester and Africa respectively whilst 65% and 33% said no respectively (Q7b – table 1.4). This is so in relation to attitudes towards height where 4% would increase the height of their babies in Manchester whilst 29% would do so in Africa (Q14d – table 2.7). This is equally the case with attitudes towards improving the skin colour with 11% willing to do so in Africa compared with 0% in Manchester (Q14e – table 2.8). Attitudes towards cloning are no different with 2% and 15% saying yes and 88% and 60% saying no in Manchester and Africa respectively (Q25b – table 4.3).

Attitudes towards discrimination per se

When asked whether respondents would remove an identified gene that would be responsible for our tendency to discriminate against one another. 39% in Manchester and 15% in Africa would not delete such a gene as against 49% in Africa and 18% in Manchester who would delete the gene.

Are the respondents from Africa more in favour of equality of opportunities and non-discriminatory principles? This does not appear to be the case considering the fact that respondents from Africa were more likely to delete genes on the basis of disability and different sexual orientation. Could it be that the respondents from Africa become more tolerant once the disabled people are born?

Reservations towards the new human genetics

Reservations about the new genetics and its regulation appear to be equally shared, with reservations being mainly concerned with the new genetics attempting to play God, to interfere with nature and the uncertainty surrounding the new genetics (Q19- table 3.4). It would appear that the reservations helped to form attitudes towards regulation as an overwhelming majority of the respondents in Africa and Manchester were in favour of regulation (44%) and (68%) respectively (Q17 – table 3.2). December (2002) reports also that a majority of the respondents were in favour of regulation amidst the concern raised by a survey carried out one year earlier where three-quarters of the respondents said that regulation and policies on the new human genetics were not keeping pace with new developments (adapted - MORI 2001)

There were similarities in the attitudes towards support for the care of disadvantaged individuals, with 58% and 69% of the respondents supporting the care of the disadvantaged by the government, as 66% and 53% from both samples would continue to support government care for the disadvantaged despite the high cost (Qs 21 & 22 – tables 3.7 & 3.8). In an earlier survey in a developing country - China, 61% of the respondents also agreed that government should care for the disadvantaged individuals rather than being cared for by individuals (Macer 1994). It could be argued that the personal choice of respondents from Africa in terms of their negative attitudes towards disability and the propensity to design may be related to the personal means of care given the fact that the same respondents by contrast showed greater support for the government to care on their behalf (unless the respondents failed to realise that care by the government is via public taxation). Even so, it could be argued, that unlike care by the government, direct personal care by parents of disabled children involves psychological and physical care and support hence perhaps the reason for termination of pregnancy (see above) and that perhaps public taxation is not a major worry for parents in developing countries where there may be loopholes in tax payment.

There are some common grounds for the need to have informed consent before our genetic information could be passed on to third parties with 84% in Manchester and 61% in Africa in favour of consent (Q24a – table 4.0). There is also a common agreement that the use of genetic tests to discriminate in employment and insurance may prevent respondents from undergoing genetic tests 22% in Manchester and 19% in Africa (Q24c – table 4.2). MORI (2001) reports too that an overwhelming proportion of respondents reject genetic discrimination in insurance and employment in UK.

The issue of international regulation of the new human genetics and the inherent eugenic results can be put into perspective when we look at human cloning and whether people would be happy to be prevented from doing so outside their own country. Here, responding to the question of whether the respondents would like to clone themselves 2% in Manchester answered yes whilst 88% answered no. In Africa, 15% answered yes with 60% saying no (See table 4.3 Q25a). This seems to reflect the response from a previous survey conducted by the *Time/CNN (2001)* where 5% of the respondents would like to clone themselves as against 93% who would not do so. What would the respondents who said

'yes' or 'more likely to' design their own children do if they were prevented from doing so in their own country? I asked: If the kind of engineering you would want is prohibited in your country, would you then be prepared to go to another country to have it done? In Manchester, 7% answered yes and no 23% respectively. In Africa, 24% answered yes whilst 18% said no (See Table 4.5 Q26). This percentage can be compared with the report by Elmer-Dewith (1994) where the respondents when asked whether we should "make it possible for nations to produce large numbers of individuals with genetically desirable traits" 8% said yes as against 88% who said no.

Specific implications for developing countries

Implications for developing countries such as those in Africa must be viewed against the background that Africans use up to 80% of traditional alternative medicine as a means of healthcare, accompanied according to recent WHO report, by increasingly adverse side effects. We need therefore to be mindful about how we incorporate the interface between complementary medicine and conventional western mode of healthcare and about how we incorporate distinct traditional values and cultural beliefs in any discussion about global bioethics and how Africans and developing countries would embrace, reject or regulate it. It must also be gauged by how others view Africa in relation to new human genetics hence it was of great concern when Lyn (2001:192) while writing about eugenics and the use of incentives such as the use of Norplant and welfare benefits in USA to discourage the unfit to have children argues that "the implementation of schemes like these reminds us that eugenic measures that are not politically feasible in the economically developed Western nations can be introduced in less developed countries, where public opinion is less sensitive to measures of this kind".

The observable trends in the responses from Africa raise some particular concerns for developing countries. The population of the African continent is expected to reach 1.5 billion by 2025 judging by the rate of population growth. It currently hosts 800 million people – inclusive of an average of 10% of people with disabilities although it is reported that this number could be higher in a more reliable data (Ndeezi 2001). It has 13% of the world total population and having similar problems commonly identified with the rest of the developing countries around the world. Africans are not immune from the impact of the human genetic revolution neither are they completely in the dark if the findings above are anything to go by. In many developing countries like Nigeria, a strong patriarchal tradition and inequality issues remain embedded in all aspects of socio-economic and political discourses not least on genderation (Osakue & Martin-Hilber 1998). These inequalities and oppression in social relations remain largely unexplored and under-reported. As a result, female reproductive autonomy in Africa where violence against women is supported by cultural traditions (Sexwale 1994) is more likely to be an illusion; thus the new genetics would not only lead to a higher tendency to engage in genetic engineering but would also reinforce female oppression as girls/women would be more likely to be forced into termination of defective embryos.

When it comes to healthcare provision, the limited funds and shortfalls in infrastructure and human resources mean that far less priority may be accorded to care of the genetically defective even though the respondents in this survey support government expenditure to care for the disadvantaged individuals. Limited healthcare resources mean that attention would be diverted to other diseases whilst neglecting the need to care for the genetically disabled (WHO 2002). It is equally a common feature that there is a significant shortage of

qualified medical staff amidst the low level of general education. The absence of educators invariably means the lack of genetic counselling within the context of pre-implantation genetic diagnosis. Would the situation be any different for the participants in Africa who would not terminate defective embryos if there were directive counselling or if they were inundated with negative information about the social, biological and physical discomfort associated with disabilities? Would the reverse be the case for those who were ready to delete defective babies for whatever reasons if they were provided with enough evidence to show that indeed the life of someone with a disability is worth living?

In the developing countries, there would be a greater social pressure to use the new gene-technologies. This may come not only in a rush to cure diseases (Radford 2001) but also in a situation where there is less tolerance towards disabled groups (Stubbs 1997a) and where mishaps and misconducts in scientific trials and application are more likely to result. This would be in relation to our differences and sexual disposition as shown by the negative attitudes towards homosexuals and disabled people (See table 2.9 and 3.0 Q15a & b). It is also the case that parents of disabled individuals are more likely to be stigmatised for refusing to use the gene-technologies to terminate defective embryos – assuming the gene-technologies were made available through the public healthcare system. The stigma may be compounded by the influence of what others are doing (See above) (Mehlman et al 1997).

The result is that for the disabled people who escaped the net they are more likely to be discriminated against due to limited resources to diagnose and to treat defective conditions in the developing countries (WHO 2002) and where disabled people are currently excluded from the mainstream socio-economic and political services/activities like education and employment (Stubbs 1997abc; Ndeezi 2001). For example, Ndeezi (2001:3) reports, “according to Uganda’s 1991 population census, 97% of people with disabilities do not have formal qualifications”. Disabled people in developing countries are not provided with enabling support, for example, structural readjustment. They are also not represented as they are denied participation in the formulation of government policies that affect them. In fact, the disabled people in developing countries were accurately described as “poorest of the poor, the most marginalized of the marginalized and the most voiceless of the voiceless” (Ndeezi 2001:4).

The ‘voicelessness’ means that informed consent is particularly needed in developing countries because genetic tests are automatically carried out without the necessary counselling services. One outcome is that the full impact of genetic information on individuals is under-investigated. Another outcome is that individual consent is conveniently replaced by group consent and where, often, individual consent is an illusion (WHO 2002). Before the awareness of gene-technologies increases further in developing countries, there is no better opportunity for the much needed regulatory structure and processes to be put in place, for example, having a body like HFEA in African countries. The need for a regulatory framework has been demonstrated by the developed world in which platforms are provided to discuss and address the inherent ethical, legal and social implications raised by the new gene-technology, for example, the public debate over the safety of GM food in July 2003 in the UK (see below).

Thus the level of genetic discrimination and stigma in relation to cultural context (for example, the impact of arranged marriages and genetic testing) is more likely to lead to an abundance of unmarriageable females. WHO recommends that further research is needed to look at the associated risk-

benefits and other implications of genetic discrimination, for example, the impact on individuals who take part in genetic testing in developing countries whereby genetic information is disclosed that may thereafter be misused in negative ways (WHO 2002).

That there should be more research in developing countries, which is compatible, sensitive, responsive, adaptable and specific to local socio-legal, cultural and political contexts, cannot be over-emphasised. There is an essential need for more research on the new human genetics to unveil social attitudes as underpinned by traditional beliefs and cultural practices, so that local ethical and international standards are not violated by the local users and service providers in countries where deeper cultural, tribal and religious values may be mishandled or misunderstood. Such research should investigate how these beliefs and values may influence attitudes to the forthcoming genetic services in developing countries. Further research is needed to provide relevant genetic information on the use of genetic services in Africa, hence the lack of references and research data that predate my findings (Haynes 2004).

As noted above, developing countries have problems of inadequate genetic training, education and genetic services. As a result, there is an absence of healthcare professionals with adequate genetic knowledge. When there is a high level of genetic illiteracy among the top level of academia, it is not surprising that 18% of the respondents in Africa have never heard of genetic engineering. The correlation of knowledge and education with views on whether or not to receive the new genetics was shown in a previous survey where the less knowledgeable they were the more the respondents were in support of genetic engineering. This was also the case in relation to how the least knowledgeable respondents thought it appropriate to practice genetic discrimination in insurance and employment. Furthermore, those who know least about genetics thought that it was against nature and thus unethical (MORI 2001). But from the same poll, however, “opposition to the use of genetic information by parents to choose the physical and mental characteristics of children is higher among those who are more knowledgeable about genetics 86%” (MORI 2001:15). Similar to the responses from Africa, PHGU (2003a) reports in the UK that 50% to 60% were ignorant about the link between GM food and our genes.

The very low level of genetic knowledge among the educated elite and educated medical professionals makes it extremely difficult to provide effective grass-roots genetic services and makes it particularly difficult to formulate genomic policies in Nigeria, for example. There is a great need for ‘science journalists’, for more grand scale research to look at the attitudes of the general public towards the new human genetics and for all kinds of partnership and network that should include scientists from the developing countries in the development of the new genetics through, for example, UNESCO (Rosenfield 1992). A joint effort is also needed to discuss bioethics and to raise the level of public education and to increase public awareness in the developing countries (WHO 2002).

If not for the Eubios Ethics Institute in Thailand, Japan, and New Zealand (Macer 1994), attitude surveys would have been confined entirely to the developed world not least because none has yet to be carried out in Africa (Lucki et al 1998). It is interesting to note too that but for the South African government, Africa would have been without any sign of national guidelines or policies on the conduct and application of the new human genetics. That there is a huge vacuum in Africa in relation to policies on the new genetics is compounded by the complete absence of a single regulatory agency to monitor its progress. Commentators in the

developed world often refer to the need to consider the 'wider' social, ethical and legal implications of the Human Genome Project and yet adopt a narrow definition of the word 'wide' to refer to New Yorkers to the exclusion of the remote citizens in Tanzania or Lagos. This dismissal is erroneously based on the assumption that the ignorant victims in the developing world are better off not knowing or that they are not ready yet to debate the ethical, social and legal implications or that they have priority needs elsewhere. Perhaps Tanzanians ought to conduct their own surveys to examine the impact of the new gene-technologies.

The introduction of gene-technology into Africa per se is not what we should be concerned about. What is of concern are the processes and application of the new human genetics and whether there is the necessary framework and institutions to manage it as well as the absence of public debate/opinion that should help to inform policy makers. On the basis of the findings above, it would appear that Africans have yet to confront the moral crisis of the new human genetics via public debate. The apparent lack of policies on reproductive technology in Africa raises many further questions. Firstly, how much do the policy makers, academics and the general public in Africa know about the new genetics? Secondly, it raises the question whether policies can be formulated if the policy makers themselves are ill equipped with genetic information. Thirdly, can policies be formulated in the absence of empirical evidence on the nature and level of disability discrimination, sex selection and eugenic practices especially when the impact of these discourses on individual and collective interests is unknown? Fourthly, can policies be formulated without public opinions/debate on the socio-legal and ethical issues raised by the recent developments in human genetics? Lastly, can Africans formulate and implement policies, for example, on the use of genetic information, in a way that ensures data protection in some corrupt systems (Moore 2004) and unsophisticated infrastructures? The process by which the recent African Union's decision on human cloning was reached and the way in which the safe use of biotechnology (refers to as a model of biosafety law) was adopted by Nigeria and South Africa exemplify the dynamics of policy making in Africa. Here, whilst Western policies were doctored and adopted by African countries without any form of consultation with interested parties and potential victims in Africa, the latter was also recommended as a model for other African countries to emulate. We should not adopt policies because our socio-economic, political, cultural and religious beliefs are different.

As African respondents show some willingness to receive the new genetics, what then is the nature of eugenic practices and the rationale behind African attitudes towards people with disability and people with different sexual orientation? The receptivity of Africans can best be understood by reference to the cultural context and cultural values (Macer 1994). Unlike the popular population campaign in China that raises public awareness, African respondents were not aware of any government promotion or prohibition of eugenic practices hence no close relationship exists between government population control and individual eugenics except when it comes to modern contraception and abortion (Su & Macer 2003). The decision to abort is left to the individuals and is dependent on whether the parents can afford to keep the baby on economic grounds. In answering the questions, the respondents were at liberty to respond without any fear of breaking any rules (Su & Macer 2003).

Ojo (1995) reports that Africans use different methods of birth control including the notion that it was considered a taboo for women to have sex during lactation until three years after the birth of a child. In Africa, the prohibition of marriage

within an extended family is often not regarded as strictly unlawful just as the age of sexual consent is not a crucial issue although these are seen as against traditional norms. However, where this is the case, the enforcement of the law and tradition is often rather shallow in some locality. A marriage between some 'distant' relatives can be consecrated in a traditional way so that any rejection is seen in a traditional sense (not on the basis of biology that identical genes may collide thereby resulting in a defective baby) and only because such a marriage is morally incomprehensible, in which case it is not regarded as eugenic (Su & Macer 2003).

My personal knowledge provides a classic example of African attitudes/policies towards others who are different, particularly disabled people. Inasmuch as government policies on the care of the disabled are hard to come by and inasmuch as the government and individuals see the care of disabled people as less of a priority, the survival of disabled groups is left to individual parents/families to deal with (Ndeezi 2001). Until the early parts of the 1980s, the Nigerian government, for example, were able to provide limited sheltered healthcare for people who were unable to look after themselves. Meanwhile, in some States in Nigeria, funds for the limited care is reported to have been withdrawn since the 1990s, in relation, for example, to the care of people who suffer from leprosy. Again, from personal observation, lepers are driven to the bushes where they are now left to fend for themselves as many are seen begging around the motorways. Some societies in Africa see the disabled person as a social menace, in their view: *we have not been able to look after the able let alone the disabled* (my phrase).

Outside the medical profession, the causes of disability are not often linked to biology. This lack of public awareness about causation lends itself to unreliable traditional myths that disabled persons are people who have committed some crime/sins etc during his/her previous life on earth (Ndeezi 2001). It is also attributable to sins/crimes etc committed by members of the family particularly the mother of the disabled person who may be accused of adultery to which, it is believed, she has refused to admit. Disabilities in the 1950s/1960s perhaps even now were also regarded as something contagious, for example, epilepsy amidst superstition and ignorance (Ndeezi 2001). From first hand knowledge (coupled with folklore stories), disabled people – including HIV victims (as with the unspoken conspiracy of the State above) were/are often devalued, scolded, stigmatised and ignored by the State and are allowed to live in situations full of inferiority complex and isolation (Eni 2003; Tolfree 1995; Ndeezi 2001). In some cases, disabled babies/children are secretly killed by parents amidst the fact that the numbers of those killed are unknown. Killing is premised on the notion that it is better to spare the child a further agony in the future. The disabled persons in developing countries are without any united and organised disability movements and are more likely to be accused of being witches/wizards and are more likely to be the targets of suspicion when things are not going right in the local community and may be seen as wanting some revenge in view of their treatment and/or disability. The erroneous extension of the traditional belief is that the disabled person becomes an 'able' person during witchcraft meetings/activities at night and that he/she could enjoy the privileges of being a non-disabled person only after trading places with an able-bodied person who subsequently becomes ill in real life as a result.

Apart from economic factors, African attitudes towards others who are different are shaped by cultural traditions. African attitudes towards homosexuality were clearly evidenced by the rejection of Gene Robinson as an Anglican gay clergyman in the US (see table also) (Dodd & Bates

2003). This is because the African concept of humanity and the resulting decisions are underpinned by strong and unswerving traditional beliefs some of which have been mixed with orthodox religions, for example, Christianity. In this case, if an act is not in the religious scripture, it is to be condemned as immoral (Orisakwe 2003). This is supported by an opinion poll suggesting that religious background does influence peoples' decision about the new genetics. Sussman (2001), for example, reports that 36% of the respondents were influenced by religious beliefs on their views on cloning and that 16% were influenced by their education as well as by formal media news (15%). The influence of religious beliefs on the decision to refuse the new genetics is shown too by MORI (2001) in which those influenced by religion were more likely to oppose the new genetics as well as the report by Time/CNN poll (2001) where 34% were shown to be influenced by their religious beliefs towards the idea of cloning.

It is clear from the data that African respondents have aversion to homosexuality as they see homosexuals as those who become what they are by choice and those who have deviated from the traditional norms. They see homosexuality as contrary to the spirits and wishes of their ancestors and that if their ancestors did not practise it, it must not be accepted as normal; such behaviour is seen as a taboo, a curse, a sign of mental illness, all of which lead to death (see above). This is because centuries of ancestral relations continue to have some significant impact on relationships between individuals and continue to influence decisions made by contemporaries. They see homosexuality as a medical condition that is curable through prayers, rituals and/or medical intervention. Whilst homosexual acts are carried out in the strictest secrecy, homosexuality is no way publicised because it is seen as anti-Bible, an aberration and a sign of moral decadence, something that is alien to African cultural and religious ways of life, and seen as cultural imperialism of the western world that must be rejected by every means necessary (Orisakwe 2003).

The corollary of this die-hard attitude (the belief that an embedded tradition once formed is difficult to change) is put into perspective when we examine the practice of levirate and widow inheritance in some parts of Africa which could be called an 'Oedipus complex' (Britton 1989; Greenberg 1991). The act of levirate and widow inheritance involves a system whereby a brother/son may inherit, as a wife, the widow of his late father/brother on a temporary and permanent basis respectively (Ciira 2001; Fortes 1983). Paradoxically, whilst it is acceptable for Africans to adjust to western ways of life, they consider certain values/practices like homosexuality, (acceptable to a large degree in the west) to be unmentionable abominations that are not negotiable by western education or philosophical enlightenment just as levirate and widow inheritance may now sound morally wrong in the West (Roper 1994).

Another problem is the question of pride and crisis of cultural identity. It is true to say that whilst cultural identity may be fragmented, fragile and multi-faceted, (Hall 1992) many Africans see economic poverty as a plague and see some benefits in the context of modernising and politicising mythical belief in witchcraft and other ancient superstition (Geschiere 1997) yet they take pride in cultural identity enshrined in a tradition that avoids the negativity of modernity. They believe that extreme extension of socio-economic and political freedom and development breed moral decadence therefore the need for a denial of social freedom for individuals who wish to break away from cultural norm. They see the relative absence of paedophiles and homosexuals in African society as a moral comfort zone – a comfort zone to promote pride and prejudice.

Resolving intercultural differences.

How then do we break into the comfort zone to resolve negative attitudes towards disabled people and people who are simply different in Africa? This is a huge and problematic task. Efforts to change policies and public attitudes need to identify the ultimate direction of change in terms of whether we are aiming for total acculturation, assimilation or integration of our differences as well as the kind of people to be changed. Whilst it need not be emphasised here that the international bioethics framework to regulate the new genetics is equally applicable to Africans, solutions specific to the problems raised in Africa must work jointly with other wider solutions. Negative attitudes as expressed in this survey and other surveys in developing countries require multiple cultural-economic intervention strategies and require a different emphatic approach. The fact that the respondents in the surveys were influenced by economic factors suggests that the provision of infrastructure for disabled people and the introduction of welfare benefits and other support mechanisms for parents of disabled people in developing countries would significantly change negative perception of disability, but this is an approach that appears to be economically unsustainable within the short term.

No society is homogenous and African communities are no exception. There are a range of traditions and opinions some of which carry unchanging ethical traditional values and unchanging conventions. Such African heterogeneous societies harbour people who may be classified as bigots and are unwilling to change their rigid and dogmatic criticism of anti-cultural developments; i.e. those who are staunchly intolerant and conservatively resistant to cultural changes and those who would maintain negative attitudinal judgement on sexuality and disability come what may. Within these societies there are also libertarians who are readily willing to adjust to modern cultural transition as they see culture as something constantly evolving. There are also people who are willing to change but who may be reluctantly nostalgic about disavowing traditional values. In optimistic terms, the starting point in our attempt to promote harmonious interpersonal relations is to focus attention on the latter two.

To bridge cross-cultural differences through changes in public attitudes one needs to address the very foundations of cultural tradition and the foundations of other forms of social relation on which the rejection of disability and otherness are based. Implementing changes within the context of different social and cultural groups in Africa calls for a need to demystify the core beliefs and mindset that underpin the perception of disability from religious, cultural, socio-economic and political discourses. Whilst it is recognised that moral and ethical traditions are modifiable, changing public negative perceptions in the context of international ethics requires a gradual process of public enlightenment in which the media and social movements such as the disability rights movement would have significant parts to play. Media and pressure groups are powerful forces renowned for helping to shape public reception of a given issue. Agents of change in Africa therefore need the assistance of the mass media and the social movement if they are to make a meaningful inroad to changing public attitudes, biomedical ethics and institutional policies. In situations where the interests of the local media are prioritised, international social movements and international media need to assist (or collaborate) with local institutions to bring about positive results in public attitudes and public policies.

In this direction, a careful but progressive approach is needed to weave individual values into collectively shared values; hence positive attitudes towards homosexuality would

require a realignment of thought processes. Thus the evolutionary process (as against the cultural crusade or revolutionary approach) to address the emergence of modernity and new equalities must be followed by a strong relentless commitment to a sustainable future. Changing embedded cultural values by way of indoctrination, therefore, would require long and concerted effort to negotiate modernity of sexuality and old cultural traditions because individual and community values in these contexts have been cultivated and maintained for many centuries in Africa. Not to do so would be seen as taking an anti-traditional approach that questions the very rationality of African ethical and moral judgement just as it would be regarded as ideological interference with traditional values and rights of indigenous people who are not keen to embrace what may be seen in the west as enlightened libertarian perspectives on disability and sexual orientation.

Whilst a given African convention may be largely unwritten, it carries with it a strong sense of legal authority and as such the present generations see obedience to current traditional authority as not only a duty to maintain but also a duty to transmit such inherited values and, in their view, sacred virtues to their progeny. It is important therefore to address negative attitudes from a legal perspective by introducing civil and criminal laws to provide a legal framework for control in Africa just as anti-discriminatory laws such as the Disability Discrimination Act 1995 and Sexual Offences Act 1967 in the UK serve to deter people from discriminating against disabled people and people with different sexual orientation. It must be noted, however, that despite disability laws and other social movements in the developed world homosexuals and disabled people have yet to be fully integrated. Thus, immediate and urgent results cannot be expected in Africa. Another extremely important way to resolve the problems of intercultural differences is to raise public awareness about the benefit of biological and cultural diversity and social inclusion. Educating the 'educated' and the public about the concept of 'live and let others live' and about learning to accept our cultural, social and biological differences is an ideal way to achieve social integration of those whose behaviours are regarded as alien but changing public attitudes through mass education has its own inherent shortcomings.

As religion relinquishes its stronghold in many developed countries, the opposite is the case in many African countries where certain orthodox religious values are not negotiable. There is the need to reconcile individuals and secular views within a multicultural society with different religious, traditional and modern values (Guerra 1994). For example, we (including people in developed countries) need to reconcile different religious and cultural interpretations of the status of an embryo that helps to shape the perception of disability, abortion, sexuality and cloning. A change agent in Africa and beyond must therefore find ways to negotiate with religious authority (authority that has a very significant influence over the behaviours of millions of people) to find a common ground in relation to acceptance of homosexuality (Bates 2004; Doward 2004). Anglican authorities recently re-evaluated their strong views on the use of condoms as a form of contraception in light of the benefits of using condoms to prevent the transmission of HIV/Aids (BBC1 News 24th September 2004). Thus if an extension of moral adjustment is to be made in this direction, a change agent must engage in constructive dialogue with religious leaders and religious industry to accommodate new frontiers not only with a view to ensuring that morality moves with modernity but also to ensure that religiosity is re-examined in terms of its unbending attitudes towards homosexuality and the resulting impact on individuals and society (Voegelin 2000) (Guerra 1994).

Correlations of surveys, democracy and regulation

But what is the relevant link between the consumer public, democracy and regulation in formulating global regulatory policy when respondents' choices may not reflect their innermost intentions in practice? Amidst the controversies that surrounded Tony Blair's wilful disregard of public opinion against the Iraqi war in polls in 2003, is it wise to entrust to officials the mandate to make decision on complex issues or to rely on the opinions of a relatively few respondents in questionnaire surveys? Should government distance itself from the data from Africa and Manchester and the data from various other attitude surveys because they are not globally representative? In relation to validity and 'predictive values' of attitude surveys, the question remains whether or not more or less of the respondents in this survey would do so in practice (Wert 2000). We can only hope therefore that no one (very unlikely) or a smaller number of the respondents would do so in real life without any clues about the implications of the choices they have made or are about to make.

These choices may be influenced by a number of socio-economic and political factors. Respondents may express their views without necessarily possessing sufficient knowledge of the implications of their choices (<http://www.news-medical.net/?id=2839>). Mobilisation of public opinion therefore may be accompanied by inadequate knowledge/information about treatment and moral discussion raised in this thesis. This is not to suggest that rational decisions made by respondents ought to have been shaped by some detailed grounding on social, political cultural and ethical dimensions. Rather rational decision could be merely simplistic or merely congruent with an individual-centred approach to their values in life.

The regulatory outcome of attitude surveys in terms of behavioural consequences is difficult to measure because of numerous variable factors such as personal experience of disability within the family and other familial circumstances or due to a single event such as a positive scientific breakthrough, scientific disaster or the result of reactions to accumulation of events between the time of the survey and the time of practice. Individual choices therefore depend on the extent in which the respondents were influenced by the internal and external circumstances and whether or not the same circumstances exist also at the time in which opinions are activated. From an international regulatory framework, national politics would be influenced by different local political systems, for example, constitutional, fundamental ethical and moral principles. One way of looking at this is to examine whether ethical values are inborn, in which case positions taken by individuals in these surveys have nothing to do with external moral conviction, information or misinformation by interest groups or public debate, and whether respondents were simply echoing public sentiment or attuning to the prevailing cultural norms.

A truly democratic government meanwhile has the political mandate to govern and lead the public rather than the other way round. One advantage of policy making by political officials, it could be argued, is that the traditional policy making processes allow policy makers the opportunity to engage in detailed scrutiny before making a final decision unlike the respondents who may spend a few minutes on a survey questionnaire. The relevance of a public survey to policy making vis-à-vis its value in empirical analysis depends on political dynamics and assessment of the current and or possible systemic impact on a whole range of issues such as the benefit and risks to individuals and communities including political, philosophical and educational orientation of policy makers and the degree to which the policy maker is prepared to risk his/her political career.

It is the policy makers who have the political mandate to exercise discretionary power to justify political judgement or to yield to public opinions. But in reaching regulatory decisions leaders need to balance various competing interests such as the sensitivity and complexity of issues that may require specific or specialised response including any shift in public opinions irrespective of whether or not public opinions have the political privilege *per se* to change the incumbent government. The decision must also note the opinions of the minority who are then forced to accept the verdict of the majority in an opinion poll as well as the competing ideology of other constituents. This would involve weighing and comparing factual information against public moral sentiments whilst considering the resultant wide-ranging implications (Holder-Williams 1997). Such political decisions would have to take on board the question about the nature, source and engineers of opinion polls to avoid being misled by 'expert public/media and other pressure groups that may well be pursuing subtle interests under the pretence of public opinions. This is because external pressure may come to bear on researchers who more often than not are able to initiate issues and topics that shape survey questionnaires leading to conclusions that respondents were never well informed and that such attitude survey results were not truly representative of public opinions. As a result, it could be argued, government (taking the view that opinions do not control government policies) may be best suited to take the lead on regulatory policy by ignoring public sentiment and refusing to be responsive to public surveys (Holder-Williams 1970).

Value of opinion polls

Opinion surveys, I would argue, are not merely based on hypotheses and probability theories because opinion polls serve some useful purposes in regulatory schema despite the possibility of change of heart or dishonesty on the part of respondents. Historical records show that public opinions are complicated, fragile and easily swayed in different directions and are not usually empirically verifiable against original standpoints, but the acknowledgement of flexibility of public opinions has neither change the value of surveys nor negated the benefits of public polls in principle and in practice (OECD 1998; Holder-Williams 1970:3). As noted above, the reality of surveys is that it is impossible to predict how respondents' contemporary views would subsequently be translated into practice except to rely on hope and assumption that the respondents would stick to the original viewpoint.

The attitude survey continues to be a significant yardstick by which to influence, educate and inform policy-making and to galvanise support for specific interests. Whilst citizens have the opportunities to take part in representative democracy, the opinions of the public are recognised through, for example, the use of referenda whereby public opinions are used to rubber-stamp or effect legislation. This is demonstrated by the use of different referenda in different countries to settle national issues such as the use of a referendum to decide issues of fundamental importance e.g. membership of the EEC by the British government in 1975 (Tolbert 1998; Kobach 1993). This is a form of direct democracy in which citizens are enabled to make policies without the involvement of politicians as intermediaries. This means that citizens can have a direct influence on how they want to be governed (Travis 2004; Glaister 2004). Public attitude surveys are used to aid political processes in which citizens are able to propose and initiate public policies through the grassroots. Some have observed, however, that despite the wide use of initiatives by interest groups only a limited number have political outcomes (Gerber 1998; Banducci 1998).

With the emergence of this brand of direct democracy, attitude surveys become increasingly useful in influencing regulatory policies and serve to shape/reform political processes not only in constraining political decisions but also importantly, in the regulation of ethics when legislators are faced with dilemmas over many of the ethical and moral decisions raised by the new genetics. In this way, governance policies and the autonomy of the State may be duly constrained by political pressure on unresponsive, inefficient and dictatorial government and at a time of public distrust and dissatisfaction with government by drawing public attention to certain issues prevailing at a given time (Banducci 1998; Tolbert 1998:171). This pressure becomes more decisive when politicians use survey findings as bargaining tools at elections to negotiate strategic decisions especially when political opinions are divided on whether or not to regulate.

Whilst the prime results of surveys may not necessarily lead to immediate policy changes, they tend to highlight important issues for relevant constituencies such as the disability rights movement, the benefits and risks to current and potential victims of stem cell intervention and helping to maintain and modify the status quo and the basis for further action. The results of attitude surveys from Africa and Manchester and elsewhere are useful in modifying the regulatory framework as they give citizens the chance to influence responsible governance policies and provide an opportunity for individuals to express their views, values and choices without necessarily being influenced by media allegiance and party alignment (Holder-Williams 1970). Respondents can decide freely on issues of individual moral values and moral convictions in life. Opinion surveys give support or lack of support to many audiences and many perspectives, however fragmented they may be, and oblige policy makers to be cognisant of public wishes. Public opinions help to generate a focal point for political discussion and provide emerging trends in public views (Burkeman 2004a/b). At the same time, they allow policy making to be more responsive and reflective of public desire. The fact that policies initiated by citizens are on the increase (fuelled by opinion polls) goes to show how the rights of ordinary citizens have become embedded in local and international political discourses (Kobach 1993; Banducci 1998; Patterson 1998).

The opinion poll industry provides a decisive influence on analytical ground for huge academic, journalistic and political debates just as political campaigns and political progress are often centred on the position of public opinions. Commentators have frequently cited and relied heavily on statistics from surveys to substantiate their position or to shed light on sensitive and important issues as survey results serve to initiate ideas, control and guard policy makers on undercurrent issues. They also complement and offer alternative ways of decision-making as well as helping to communicate the ideas of the governed to governors by stimulating government to become public-conscious. International attitude surveys prevent monopolistic and paternalistic government approaches to regulatory frameworks, thereby limiting constraints imposed by regional and cultural values and political dynamics (Kobach 1993; Ginsberg 1964).

This view raises the question, however, whether there comes a point at which the popular decision is so overwhelming that it almost requires a dictatorial regime to overturn the voices of the masses. Whilst various and yet isolated public attitude surveys in different countries cannot be taken to be international referenda, national referenda tend to give power to the citizens in relation to controversial issues whereby the power of the representative democracy becomes

minimised or superseded. Global regulatory frameworks become problematic in an attempt to reconcile different States' recognition of public opinions from one or two countries. In Switzerland the citizens control referenda so that the government is more prone to act on wishes of the people who may initiate issues on referenda agendas. But in other countries, especially non-democratic countries, the acceptance of public views becomes difficult where provision for direct democracy is not endemic in political systems and where government tends to pay less attention to public views (Kobach 1993).

Making a case for regulation

It is worth reiterating the fact that the core theme underlying this thesis is the necessity for global regulation of libertarian eugenics and that the approach here is to mount a holistic argument in favour of regulation. To ignore the necessity for regulation is to promote its discriminatory implications for individuals such as negative attitudes towards disabled people and other disadvantaged groups as raised and to leave untouched the problems of unlimited reproductive freedom for parents and others to do whatever they like with human embryos. Not to focus on the necessity for regulation is to be apathetic about the pace and the uncertain risks accompanying developments in the new human genetics and to ignore our historical past.

Despite reservations about whether public opinions as expressed through attitude surveys are indeed democratic enough and whether the findings in Manchester and Africa are enough (bearing in mind factors such as the number of respondents) a case can be made for global regulation in view of the above issues. In addition, the data from the survey in this chapter and other similar surveys offer crucial evidence in the form of overwhelming support for the need for regulation and revealing too that control needs to be addressed from a global perspective. A number of findings from the data in Manchester and Africa can be used to justify a case for regulation, for example, that people are prepared to delete embryos on the basis of minor or severe disabilities (see above). The fact that an overwhelming number of respondents agreed to global regulation is by itself sufficient to justify a case for regulation. This is in view of the fact that the existing local control framework remains skeletal, inaccessible, poorly co-ordinated and poorly monitored and that in many areas/countries policies are absent leaving current and potential consequences largely un-assessed (Blank 1990; Tribe 1973; Dixon 1997).

As a result, whilst attitudes vary from time to time due to ambiguity and inconsistencies in semantics such as the language/terminology used in survey questionnaires, it is possible to make a case for the need for universal control of the new genetics. Justifying a case, however, may depend on how individuals view the issue. First, the fact that the respondents were overwhelmingly fearful of undergoing genetic tests or disclosing genetic information to their employers/insurance companies because of the resultant genetic discrimination should suffice by itself to raise a concern. Second, that an overwhelming majority in this survey are in favour of regulation is a confirmation of an earlier survey in which an overwhelming majority also supported regulation by an international institution like the UN or WHO (Macer et al 2000). That people would travel (have done so) to another country to achieve their engineering aims is another reason why international regulation is necessary (see also data from Manchester and Africa). Noted but not addressed are several overviews suggesting innumerable points for discussion as there is much anecdotal evidence that substantiates current and potential negative implications of the

new eugenics (e.g. the 'signs of the times' in chapter 2 above). It is evident that my findings echo other similar studies in terms of how attitudes towards disability in developing countries (Africa and China) are unfolding. This significant finding cannot and should not be dismissed without further investigation if we are serious about the implications of DIY eugenics from a global perspective.

As discussed above, a comparatively higher proportion of respondents in Africa are ready to embrace the new genetics. The tendency is reflected in responses to all the questions in the questionnaire. Could this be attributed to the low level of awareness of genetic engineering which otherwise would have alerted the respondents more to the potential benefits and risks? Could higher levels of genetic information and public debate/exposure (as in Manchester) have shifted the stance taken by the African respondents? There is no doubting the fact that some of the reasons for the negative attitudes towards deformities are socio-economic, as disabled children would have no particular use to parents in developing countries like Nigeria and China except to become liabilities in political systems that have no welfare system to assist parents and carers of disabled people in contrast to Manchester where social services are available for people with disabilities (Su & Macer 2003). A look at the 'general comments' shows the overwhelming negative attitudes towards homosexuality among the African respondents and suggests a historical revulsion against what the respondents refer to as 'abnormal' an abomination, unnatural and against religious and cultural norms. Whilst the number of respondents who said that they would increase the IQ of their babies was 11% in Manchester, this is perhaps insignificant from the viewpoint of those who are in support of the new genetics on the basis of its having a 'small impact on the gene pool'. It cannot, however, be emphasised enough that small though this percentage is, it raises some serious concerns about the impact on a single individual as well as aggregate implications for the gene pool and that 50% in Africa is particularly worrying in a 'policy vacuum' and unsophisticated monitoring system where the class divide continues to impact on disadvantaged individuals (See Q14a - table 2.4).

What these findings suggest is that as people argue in the west that the new genetics would lead to hope of eliminating debilitating diseases and against disadvantaged individuals, the impact is more likely to be doubled for Africans. Therefore when you think that the possible positive impact of the new genetics would be 20% in the West, it is more likely to be 40% in Africa - which may well be good news. On the other hand, when you think that the negative impact would be 20% in the West, and is more likely to be 40% in Africa, this may be bad news for us. This is more reason perhaps why we in Africa and indeed, developing countries in general ought to be more prepared than anyone else, and indeed have a need for global regulation.

National regulation would be ineffective as exemplified by practices in Germany in relation to PGD where a ban means that Germans/companies simply go to England to circumvent the restriction on stem cell therapy and cloning or when couples in England now travel to America for designer saviour siblings etc (Hawkes 2002; Fukuyama 2002). Here too, a significant number of African respondents were more willing to travel to other countries for this purpose (see above). For Macer, an international regulatory approach is required because of the inability and/or unwillingness of some countries to formulate adequate guidelines and because there are already "*precedents for international law to protect humanity's common interests*" in almost every socio-economic and political discourse and because of the "*shared biological heritage*" and global "*perceptions of bioethical reasoning*"

(Macer 2000:139). It is therefore acknowledged that the new genetics raises issues of commonality - shared impact by virtue of humanity; thus there are areas that require barriers beyond which transgression is prohibited and that we cannot ignore developments in genetics as we are all affected by its wide-ranging ramifications (Blank 1990). The European Communities' common scheme is already monitoring and approving the use of drugs on an international scale (Walser 1998; Fukuyama et al 1999; Macer 2000). As Warnock (1967) argues in a different context of harms to future generations, moral principles work best at universal level rather than being group-bound in order to avoid moral conflicts and non-cooperation arising from specific groups.

The common harmonisation could be justified on the basis of historical scandals associated with self-regulation by scientists and industries (McNeill 1993). The historically bad records of inefficiency levied against international institutions should not deter the setting up of another institution. One major aspect of human development is the ability to learn from mistakes and bad practices. Learning from the current loopholes and history is not a guarantee against failure but the regulatory odyssey has to start from somewhere. If it is to start, it should start from the precedents and platform set by institutions like HFEA in the form of a new global HFEA. Such a move "requires the nation-states to harmonise their regulatory policies" (Fukuyama 2002:194) and requires others to adopt new guidelines on ethical practices (WHO 2002).

Thus the content of this international regulation at the moment remains vague and uncertain and it is indeed very difficult to formulate or to accept common legal grounds because of the diversity of national and individual values, customs, traditional, religious, cultural and political practices, for example, emphasis on individual rights in the US (Blank 1990). As with international treaties, there are further problems of ratification, adoption and adaptation to unified norms by individuals and communities, hence the failure to commit to international obligations (Gruchalla-Wesierski 1984; White & Abass 2003). This is illustrated by the current unhealthy economic relationship between the US and the European Union (EU) over whether the imposition of a 5-year moratorium by the EU violates the rules of the international trade agreement because according to the Americans the EU fails to provide 'scientific evidence' of the risk of genetically modified food to the public. The EU insists that the moratorium is in line with the international trade regulatory rules that allow nation states to take into account national interests and to develop their own appropriate approval procedures in accordance with the fears and concerns raised by the national public (Pegg 2003).

Thus any convergence at international level would require "persuasion, negotiation, economic and political leverage" (Fukuyama 2002:192-4) if we are to unify the different ideologies, culture and philosophies of each country including the notion of political sovereignty of each member nation. The independence of nation states inhibits the ability of an external body to investigate internal practices for reasons of rights and/or treaty violations - violations underpinned by subtle ideological and socio-economic interests (Kohona 1985). However, the role of a centralised regulatory agency/framework is to ensure that an international approach pays attention to internal standards, diverse views and cultures rather than operating under an assumption of uniformity (Macer 2002).

There is a further reason for a global bioethics framework. That is the need to solve communications problems between countries because of fragmentations in our understanding of our different cultural and moral values. Regulation would be impossible if participants were unable and unwilling to

understand mutual languages, culture, religion and moral standing, indeed, misunderstand the direction of the new genetics and humanity. A global view of the success and problems of the new genetics would enable 'affected' individuals and countries to have an independent voice in regulation. At the moment, developing countries and 'disadvantaged publics' in both developed and developing countries, for lack of means, knowledge and interest, are unable to participate fully in public discussion and are neither encouraged nor enlightened about the morality of the new genetics. Yet it is the disadvantaged groups that are by every measure more likely to suffer from regulatory failure. As a result, non-scientists in the west and consumers in developing countries are seen only as simple consumers and recipients of 'handout policies'.

There needs to be a shift from the regulatory model dominated by the current west-led scientific-bureaucratic decision-making process towards an international platform for public debate and consultation. Full integration would enable a wide range of interest groups to air their views and to contribute (Black 1998). Globalisation in this context raises, however, a difficult question in relation to how to ensure global views are heard when there are no public discussions or social groups in the whole of the African continent (See above). We need to shift our tunnel vision to a diversified view because the on-going genetic revolution creates cross-border moral crises that are intermixed with scientific and non-scientific issues. It is only fair to re-examine and redefine a common ground for re-conceptualisation of ethical and moral values and the implications across professionalism and across national boundaries (Black 1998).

The requirement of a centralised institution is not a panacea and therefore cannot alone solve complex regulatory problems. The legal framework needs to be complemented by other regulatory models if regulation is to work. The crucial question is how to begin to implement regulatory sanctions in liberal society without a big brother surveillance camera violating the very essence of our rights to privacy. Regulation in this thesis is seen as a process that goes beyond traditional efforts by government to regulate the activities of organisations or individuals and encapsulates individual self-restraints through self-discipline and public education and where everyone takes ownership of regulation (Blundell & Robinson 2000). Regulation here looks at how individuals in their private bedrooms could be prevented from unreasonable use of their reproductive rights amidst the availability of a range of eugenic techniques to design the characteristics of their babies for cosmetic purposes without taking into account the interests of potential victims. The need for caution comes from the fact that women today are able to confirm pregnancy within a few minutes in their own private homes by way of a cheap testing device easily obtainable from their local pharmacy.

Conclusion

As noted above, subtle pressures may come into play when opinion surveys are conducted. Viewed from this angle, the barometer of public attitude surveys is open to possible bias, distortion and manipulation. When this happens, it raises questions about the reliability of methods, interpretation and presentation of survey results. Whether the result is sufficient to serve as 'public' is one issue and whether it is democratic and representative enough to enforce global governance is another. The lack of preciseness of opinion polls is evidenced by the election result in 1970 in which the Conservative Party won the British general election contrary to the numerous opinion polls, which overwhelmingly predicted victory for the Labour Party (Hodder-Williams 1970). It would

be misleading indeed naïve, to suggest a regulatory framework on the basis of a single survey in Africa and Manchester alone (however enlightened they might be) without further deliberation and consultation. That noted, however, government must pave the way for the views of the public whether in a democratic or non-democratic system or within educational setting.

What is clear from the data is the necessity for global regulation in view of the fact that people would use the new genetics without knowing much about the risk and without paying attention to the impact of their decisions on others. More importantly is the fact that people would use the new developments in human genetics on the basis of their traditional, cultural, educational and moral values just as socio-economic factor may come to have some significant influence on their choices. Policy makers need to take appropriate responses to the descriptive data presented here, and already governments have agreed in principle through their signing onto international declarations on these issues agreed in UNESCO.

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Appendix

This questionnaire provided 40 opportunities to make comments. If every respondent had commented, this would have amounted to 43,960 comments from a total of 1099 respondents in Africa and Manchester. Given the nature of this paper, it was inappropriate, indeed a huge task, to repeat every comment here, also because many comments were very similar. However, I have extracted some of the comments that reflect (in my view only) a representative message/opinion from the respondents. The aim here is to provide an overview flavour of the thinking behind some of the answers given by the respondents. Where there is no 'question' numbers (i.e. Q) attached to comments, such comments were taken from the general comments on the survey.

Some selected comments from respondents (Unedited)

A = Africa; B = Manchester

- A493 Q14e Yes; because 'so as to have the right proportion and sex I want accordingly' Q15a yes 'so as not to make him look stupid and irresponsible' Q15b yes 'so as not to spoil her personality in the eyes of other people'
- A487 Q14e No; 'because I would like my child to have the natural colour i.e. mine or his father's or mixed (both)'. Q15a & b More likely; 'baby is still in the womb if possible. The factor that influenced my decision being that I would not want to bring forth a child will constitute nuisance or bring problem to him/herself and to myself'
- A486 Q15a & b More likely; 'on rational and moral ground'. Q16 More likely because of 'equality of all men'. Q17 Less likely; because 'monster may outnumber Angels and human race will be in utter confusion'. Q25a No; because 'I shall be unique. I am a social animal; though my physical appearance could be copied, my experience which determine my behaviour sometimes, cannot be copied, so what is the big deal about this cloning of a thing?...man must be very careful with this idea of cloning. It could be dangerous. Evil men may take greater advantage of the whole situation'
- A485 Q14e Yes; because 'unequal treatment of blacks especially outside the black continent'
- A479 Q10 Yes; because in most Nigerian culture or in my culture specifically, a couple that does not have a male child for example, is said to have failed in life because there will be no male to carry on the family name after the demise of the father' Q11a Yes; because I believe the techniques to be used includes marrying a compatible partner whose medical history is clear or free from any genetically transmitted disease, and also making sure that the genotype match each other so that the occurrence of a sickle cell child would be ruled out'
- A464 Q 11d 'if I design my baby i.e. making him to have good health, I would be saying that God is not perfect or

- competent' Q14e No; 'a man is not proud of his colour is not fit to live.'
- A458 'I would want to know more on genetic engineering, you can e-mail me at ideleevbu@yahoo.com'
- A446 Q14e No; 'black or white what matters is what is on the inside' Q15a less likely; 'he has a right to choose what he wants to be to control himself or subdue urges which are rather absurd' ... 'yes, I would structure my child in accordance with my desire but the truth is my religion forbids it. As much as I desire it my religion will restrict my decision'
- A444 Q9 Yes; 'I choose a boy because I am a man, and he will be there to inherit my name when I am dead'
- A442 Q9 Yes; 'because of the belief that a male child is more capable to withstand difficulties in life' Q15b Yes; 'because lesbianism in Africa is a social aberration, and cultural taboo therefore it is improper'
- M 307 To decrease the chance of a disability would be a marvellous thing if the child would suffer, but to make your child definitely heterosexual would eradicate free speech and choice and that is morally wrong in my opinion'
- M316 Q15a No; I am homosexual so I would be more comfortable with a gay child'
- A453 Q15a No; 'I don't believe homosexuality is genetically transmitted. There are other ways of correcting such a vice'
- A449 Q15a Yes; 'my religion and my common sense do not agree with homosexuality and I hate them so I will stop it immediately if possible because they are abnormal'
- A445 Q15a&b More likely; 'because I do not want my child to be gay'
- M300 Q15a, No; They are who they are, sexuality does not make someone a better or worse person'
- M281Q15 yes; Amazing! The world would be a better place
- M267 'If I have contradicted myself it is because this topic, as you realise, is terribly complicated but overall I feel engineering of personal physical traits is wrong'
- M251Q22 No; how much do they spend on warfare?
- M340q22 No; 'people all over the world live in poverty and these kind of funds are needed by the poor of the poorest in our world today'
- M326q14a No; surely, IQ is more environment than hereditary/genetics. There is no quick fix to a better life'
- M326q11b No; 'Who decides what is classified as a degenerative gene? Ginger hair? Homosexuality? These are choices we should not be allowed to make for future generations' As a Quaker, I believe that we should leave some aspects of our life to providence. I don't think I have any moral rights to make the choices you outlined'
- M327q20a yes; abortion is not only to help the mother but is a way of preventing physical and emotional pain in the child'. Q15a No; what is wrong with being gay? I don't feel that it is a bad character trait and that it would affect my child's health or ability' Q14a no intelligence is not everything creativity and physical ability are just as important'
- A483 Q20a Yes because 'I can not be glad having a child that is likely to die after all I have suffered to bring him/her up' Q20b Yes 'having the knowledge of disabled in born baby is as good as terminating the pregnancy'
- M308 I believe medical defaults are a serious concern and could lead to a poor quality of life'
- M345q13 More likely to influence...but I would not but my culture favours 'perfect babies'
- M349 'Genetic engineering would distort the human race beyond recognition'
- M 355 'parents should love their children whatever they are like and so should not want to change them'. Q11b No; 'because God designed us to be different – if we all designed our children they would be likely to be very similar-not as God intended, in my opinion'
- M358q20a Undecided. Very hard to know how you would react to such a situation until you are actually faced with it. Would like to take moral high ground and to say no but in reality do not know how I would react'
- A475 'If adequate resources are provided for the realisation of the aim of genetic engineering, I think to a great extent human disorder and abnormalities will be greatly reduced'
- M359q19 play with nature...nature has a way selection for a reason – tampering with this may cause problems'
- M362q7b Yes; I think it will happen regardless whether it is legal or not'
- M365q20a More likely...depending on the type of problem'
- M370 'The whole thing seems far too unnatural to me'
- M373q14b More likely to do so ... 'for the simple reason that if everybody else was doing it, then your child with lower IQ is at a distinct disadvantage when it comes to competition for well paid jobs etc. and thus a higher standard of living'
- M376q20a Undecided... 'Very hard question to answer without being in the situation'
- M37814b Yes, it would be difficult for the child if they were far behind due to a lower IQ'. Q16 No... 'it is more valuable to overcome our initial thoughts and feelings, makes you a better person'
- A461 'Why should we go all the way to think about improving our genes when it is obvious that we were all created in the image and likeness of God. So we are perfect in his own way. Genes should be left the way they are even if death appears in the picture God knows all'
- M375 'Very interesting and also very worrying. I hope I am not around to see a world full of clones'
- A460 'I feel really sad about this cloning issue, I think it is an evil thing which should be prohibited'
- M341q25a Yes, I am twin
- A471. 'First people should understand that genetic engineering is science i.e. man-made and is bound to malfunction or fail so in the process of that what happens when this thing fails?'

Emergency Management in Public Health Ethics: Triage, Epidemics, Biomedical Terror and Warfare

- Hans-Martin Sass, Ph.D.
Zentrum Medizinische Ethik, Ruhr Universitaet
Postfach 102148, D-44780, Bochum, GERMANY
Email: sasshm@aol.com, sassh@georgetown.edu

You govern a kingdom by normal rules; you fight a war by exceptional moves; but you win the world by letting alone (Tao Teh Ching, no 57)

1. Normal and Extraordinary Situations

Life has normal and abnormal times; this is true for individuals, families, and also communities and states. There are certain technical and moral norms which guide our behavior, make us successful and reliable in everyday life and in professional life. These guides govern our behavior and the expectations of others. The rule 'love you neighbor', known as the golden rule in all cultures. We define good people in contrast to bad people as to be those who act of an attitude of

compassion, who care for others, in particular for those who are close to them: parents, family, neighborhood, but not excluding strangers. *The concept of compassion is valid for everyone, for personal and for professional activities.* Businessmen should not exploit or steal or otherwise hurt their customers. Generals have to fight the enemy, not their own government or the people of their country; homebuilders have to build stable and reliable houses. The medical profession, physicians and nurses, have their own code of ethics, more clearly defined in medical ethics: a great physician has to combine expertise and ethics, professional knowledge and human compassion. He should not make difference between his patients and treat everyone fairly and just; he should treat everyone professionally and morally as if he were his own father or mother. As famous Confucian doctor Sun Simiao in his book 'On the Absolute Sincerity of Great Physicians' wrote: *'A Great Physician should not pay attention to status, wealth or age; neither should he question whether the particular person is attractive or unattractive, whether he is an enemy or friend, whether he is a Chinese or a foreigner, or finally, whether he is uneducated or educated. He should meet everyone on equal grounds. He should always act as if he were thinking of his close relatives. (Sun Simiao: On the Absolute Sincerity of Great Physicians).* In the Western world Hippocrates, who is called the father of Western medicine, expressed the same ethics by means of an oath to be sworn by physicians: *'Into whatever houses I go, I will do so only for the benefit of the sick, avoiding all willful injustice and harm.'*

In modern times, we have certain requirements for the ethics of a good physician. These requirements are based in the tradition, are taught in medical ethics classes, but above all by role model and behavior of clinicians, doctors and nurses who are exemplary teachers of their students and rightly called masters of the arts and sciences of healing, i.e. combining expertise and ethics, professionalism and compassion. The requirements for a trust-based communication and cooperation with the patient and the family include the following norms and standards: (1) the care for the individual patient who is your first obligation; only thereafter come obligations to the family, the hospital, society; (2) every intervention requires the information and the consent of the patient [or his family] out of respect for the dignity of individual values and personal choice; (3) do not treat without informed consent; (4) treat everyone fair and equal, e.g. do not make a difference between the poor and the rich, men or women, or people of so-called social worth such as public officials or dignitaries; (5) treat those who need the help most, first. It is the usual practice that emergency care is given priority over routine treatment in hospital wards; doctors are called to the emergency room and other patients and non-emergency procedures have to wait.

2. Triage In Disaster, Catastrophe and in War

The case: *A bus accident has happened on the road. All 30 people are hurt, some very severely and might die if not helped immediately; among the passengers is a nurse who could help, but she is also hurt. A local ambulance with one doctor and two nurses with some emergency equipment happen to come by. The doctor recognizes his mother to be among the more severely hurt. How would you set priorities, if you were the physician, would you treat your mother first, or those who might die if not helped immediately? Would you give the nurse a priority treatment in order to get one more trained nurse to help?*

The bus accident case presents a situation of triage. Triage occurs in natural or man-made catastrophes, in severe epidemics or endemics, after acts of terrorism and in war. There are established rules of professional conduct and ethics of triage; for medical as well as ethical reasons these rules are

different. The general rule is: safe as many lives as possible in the shortest possible time or in the time available. Such a triage ethics is reverse to what is professionally and ethically mandated in normal situations. Triage ethics include: (1) give preferential care to of medical or management worth, who can assist you; (2) care for those first, who are least hurt; (3) allow those, who are hurt most, to die; (4) provide treatment, if necessary, without consent.

Of course, there will be a professional and very personal conflict for the doctor in postponing the treatment of his own mother, actually putting her into the sequence of a treatment list, which contains the easiest cases first and the most complicated cases last, i.e. violating the principle of 'filial love [xiao] for the benefit of 'neighborly and patriotic love' [zhong]. The ethical reasoning give for the triage situation is the reverse commitment of the physician and the health care system to safe life: save as many lives as possible and don't safe those lives, which need it most. Giving the nurse a preferential treatment contradicts the principle of fair and just health care directly, but it helps indirectly to increase the quantity of care given to everyone on the list of a sliding scale people needing less help and more help and very much help.

NATO instruction in a handbook on 'Emergency War Surgery' [www.vhn.org/Ew_surg/ch12/12Triage.html] differentiates between ordinary and extraordinary triage: *'Ordinary triage classifies the wounded so all will receive optimum care, while mass casualty triage treats the injured according to salvage value when the injured overwhelm available medical facilities and not all can be treated.* In making triage decisions, pressure of time to treat certain cases earlier than others complicates medical and ethical decisions even further. In traditional virtue theory, this would mean that 'neighborly and patriotic love [zhong] in those extreme situations becomes a more urgent virtue that 'filial love' [xiao] and that 'colleagues' as potential partners become preferential treatment.

3. Fighting Epidemics

Case Study: Two dozen family members and friends attend the marriage of Mr. and Mrs. Wang. They come from different provinces, some even from abroad. During the festivities they got infected with a highly lethal virus, such as the SARS virus, Ebola or a pathogen similar to the H5N1 virus. Twenty die; only four survive. By using high-tech and low-tech modes of transportation, they spread this highly contagious virus around many provinces and around the globe, causing one billion people to die. The case of the Wang family spreading a highly lethal virus around the globe results from the easiness, safety, and affordability of global travel. Global travel is a high achievement made possible by a combination of high-tech developments in hardware and software and skilled businesses and good governance; it is definitely a contribution to global enterprise, communication and cooperation, not at least to better understanding each other. But global travel can spread dangerous viruses and other dangerous material more easily around the globe than before. Countries are fixed to their respective geographic place, people, viruses, materials are not. Two different scenarios describe the destructive potentials of the high-tech context for human health, human life, and human culture: (1) the 'natural' spread of global diseases, and (2) the terrorist, aggressive, or criminal use of pathogens to kill or to terrorize. For scenarios, ordinary citizens and public officials may (3) translate classical theories of 'just war' into the high-tech context of biomedical terror and warfare.

(1) Global mobility causes global spread of infectious diseases: We don't have to wait for terrorists, criminals or foreign countries to use biomedical devices for killing, terror or

warfare. High-mobility of people, made possible by integrated global travel, and global networks of trade and commerce make the spreading infectious diseases easy and dangerous. To fight these side-effects of the high-tech context of the modern globalized world, high-tech interventions are necessary. First among those high-tech defenses are (a) a high-tech research capacity, including the education and continuing education of epidemiologists and other experts, (b) a high-tech infrastructure of informing and communicating with experts and, even more important with citizens. Of particular importance is the full, clear and easy to understand information and advice to all citizens about the dangers, about self-protection, and about shelters or facilities for help. If full and easy to understand information is not given, then public authorities will lose trust and people might not follow advice and instructions. Of secondary nature, but unavoidable and probably less effective if not supported by well informed and trusting citizens is the control of travel.

To prevent the spread of the disease, ways of spreading have to be blocked rigorously; this might include the total stop of mobility for people and some merchandise. Of course, a few or many civil and human rights will have to be restricted. Following the minimax principle, such restrictions on travel and mobility need to be balanced against the lethal and contagious character of a particular disease and the extent of such a temporary restraint needs to be communicated fully and openly. Also, the establishment of an independent governance and monitoring committee would be highly advised for two purposes: to control actual restrictions and make those who are in control aware that they are monitored, and to keep and preserve the trust of the people, who suffer under those restrictions, and later report in public on their findings. Unfortunate, as these destructive side-effects of a high-tech world and highly mobile people are, they are just a side-effect, not a dilemma which would call to reduce global travel and mobility. People and viruses can travel geographically, countries cannot; therefore countries are obligated to restrict the movements of people and viruses. This includes unfortunate actions such as quarantine facilities, mandatory inoculation, restriction of movements, and other burdens on individual lives and lifestyles.

4. Public Health Ethics and Acts of Terror and War

Here is a slightly different case: *Not the nice people of the Wang family, but a handful of neurotic or fundamentalist extremists, ready to commit terror and killing via their own suicide deliberately infect themselves with a highly contagious and lethal virus. They 'distribute' the deadly virus not accidentally as the Wang people did, but deliberately. They strategically infect many other people who then will infect many more on a global scale: in buses or subways leading to airports, in movie theaters or sports events, in planes and trains.* Many pathogens in military or research arsenals or new strains of pathogens or deliberately modified and even more deadly strains can be used for that purpose. Biomedical terrorism and biomedical killing is a side-effect of the modern world of global integration; it is also a criminal act of highest danger which needs to be dealt with accordingly. The already mentioned instruments of high level of research, readiness to test, to inform, to advise and to react by immunization, restriction of mobility, and quarantine need to be used for the protection of innocent citizens and of humankind. But levels of uncertainty and risk are higher than in naturally occurring situations of medical triage or endemic infection catastrophes, because of the deliberate strategic destructive powers of evil-doers. There is a variety of scenarios of modern high-tech biomedical destruction, terror, and war: Evil-doers might work alone or with a few friends, might have support networks, get

help or encouragement even from governments, or governments themselves might use biomedical warfare.

(a) In cases of biomedical terrorism, only a few might be killed because of poor planning by terrorists or swift reaction by public authorities. As one purpose of terrorism is killing and the other purpose to terrorize the survivors and to breed scare and fear, it is very important that authorities and experts give the lay citizen all necessary information of how to protect herself or himself and how the pathogen lives and becomes distributed; only then will the citizen feel some sort of power over the terrorist, the attack, the terror and the angst and fear.-

(b) When and if terrorists work alone in small cells, the best defense and prevention against all forms terrorism and radical discontent in society is to support healthy cultural and ethical environments, inform and educate the people to be risk competent and vigilant and responsible citizens. Global high-tech networks of communication and travel allow good-doers as well as evil-doers to work successfully in reaching their goals. We may call the situation a dilemma; being strongly in support of technology as a tool to cultivate raw nature and uncivilized societies, I rather call it a side-effect we need to be aware of and protect ourselves against.-

(c) Terrorists most likely will have direct or indirect support from international groups, even from governments, alike the sea pirates always had. If this is the case, then those groups and governments need to share the blame and punishment and be exposed publicly.-

(d) If biomedical killing is one of the options seriously contemplated by governments, the best defense against those dangerous weapon for killing masses of innocent people are a high level of research and preparedness and, unfortunately, a policy of threatening to retaliate similarly. During the times of the Cold War this was called the strategy of 'mutual assured destruction (MAD). The acronym MAD, when not read as acronym, means mad, irate, imprudent, senseless, i.e. it makes the calculation to win for a potential aggressor too uncertain and also the probability of losing one's own population and power. For an intellectual and academic ethicist without real responsibility and power in those situations, it is futile and irresponsible to even evaluate the arguments pro and contra in analytical and ethical terminology; it will be the very personal responsibility of those in public office to make such decisions, which are beyond human capacities to calculate, and to live with those decisions for the rest of her life and in history.

(e) It has been mentioned that protection of certain high-tech biomedical research from patenting and public knowledge would be necessary to curb dual-use or abuse of knowledge for terrorism or other immoral use, in particular methods used to modify microbes to make them resistant to drugs [Kaiser 2005]. As secrecy this might be a means to slow the distribution of knowledge, centuries of technology development have shown that firewalls against double-use or spin-off rarely work in the long run. But certain principles of governance to prevent potential abuse of biomedical knowledge definitely is warranted, also in scientific publication and patenting. But then, potential terrorists and mass killers do not need to develop their own, potentially more deadly biomedical weapons, as the arsenals of biomedical research are full of deadly pathogens. Also, pathogens such as dangerous forms of flu or other viruses will develop naturally and evil-doers, in particular suicidal killers, will find ways to infect themselves and infect as many people as possible before they might die.

5. Does Crisis Ethics Justify Exceptional Ethical Moves?

Is the fight against biomedical terrorists and killers of any kind a war and thus allows using methods and means, which are ethically accepted in wartime? Furthermore: does the

same apply to situations of emergency caused by natural disasters or man-made catastrophes? Is the possible destruction of large numbers of people and culture so eminent, that extraordinary means are justified? European military theory and ethics, similar to Chinese military theory and ethics, has as set of principles which need to be recognized to fight a just war. There are five requirements to justify a war as a means of last resort: use of power must legitimate; it must be a just cause; it must have the right intentions; it must be the mean of last resort; it must be an obligation (*potestas legitima, causa justa, recto intention, ultima ratio, modus debitus*).

(1) The person or institution using power must be legitimate. This definitely was and is the case for elected government which has the obligation to protect its people. But in modern times, particularly in the high-tech context, professional organizations such as those of engineers, physicians, internet experts have a legitimate power to advise governments and to be partners or executors of powers in the protection of the people. People who would be high value because of their skills, would get preferential treatment, because they will be valuable assets to fight epidemics or situations of triage. Not only generals and high public officials are essential assets in fighting catastrophes, whether natural or man-made. Actually nurses or doctors are of higher immediate value than high bureaucrats who do not bring any special skill to situations of triage and great danger to a high number of people.

(2) The cause must be just, i.e. it must serve the purpose of protecting innocent people and the population for which the government is responsible, in modern times even responsible for the survival and health of the global population. In the case of biomedical destruction, but causes would justify the exercise of warlike powers. It is under discussion, whether or not preventive war is justified as the fight against microbes, once spread, is extremely difficult in biomedical and epidemiological terms, but also in terms of protecting civil and human rights. Saving people's life always has been and always must be the highest order of every compassionate and civilized person, especially of physicians and health care expert and of high public officials.

(3) The use of war or warlike powers has to come from the right intentions, i.e. the argument that one wants to protect the people must be serious; it would unethical and unjust to use that argument only to build a stronger power base for oneself. A means to check this requirement is to check whether the means used, are precisely appropriate for the purpose. Temporary restrictions of civil liberties never are allowed for the purpose of gaining more power or hurting other parties or persons in the process of politics and business, or for enriching oneself.

(4) War and warlike situations need to be the means of last resort, after all other means to protect the health and life of the people have been exhausted. In combination with other principles such as highest levels of information, civil ethics and public preparedness, citizens will understand and support the measures taken on their behalf. Restriction of civil liberties, such as quarantine and treatment or immunization against a person's will, must only be used as means of last resort. Other public health activities such as information campaigns requiring mandatory attendance are of lower impact on civil liberties.

(5) Finally, the exercise of warlike power needs to an obligation, a duty of those who resort to these interventions and acts as a last resort. For public officials the highest duty is the protection of the people, their lives and livelihood; this is a common-sense duty, but also supported by all religions, and by Confucian and socialist reasoning. It is important that everything be done to avoid situations of high emergency and

danger to high numbers of people, i.e. prevention of catastrophes by means of vigilance, safety regulations, education of experts and people, and quick responses, which might keep the proportions of disasters as small as possible.

Thus, natural and man-made disasters do, indeed, justify using the model of just war under the condition, that these five specific requirements are met. It would be advisable that ethicists and strategists in public office and in professional organizations develop more detailed lists of principles for monitoring the exceptional powers given to or taken by those who act in warlike situations in the high-tech context.

A personal word: It is extremely unpleasant and uncomfortable for an ethicist to argue in favor of restricting civil rights and liberties and in favor of abandoning people in severely pain and suffering and helping those who are less sick or hurt. My moral and intellectual background comes from childhood experiences of the 2nd World War in Europe and the student and intellectual revolution of 1968. I have seen some of the immoralities and atrocities associated with times of war and after-war. I also cherish the civil rights of free and open modern societies. I hate war and I hate everyone who takes away civil rights from people without an extremely strong and persuasive justification. However, the dangers of high-tech biomedical attacks and destruction are so threatening, that I strongly feel that the just war theory and ethics must be employed in evaluating and in guiding the situation those responsible in public office, experts in their specific fields, and above all educated and responsible citizens find themselves in the context of high-tech biomedical risks and options. Unfortunately, it cannot be excluded that sooner or later a natural disaster such as a new bird virus or any other pathogen might develop to which humankind is not immune. In the global situation of high mobility of merchandise and people, such a contagious pathogen can spread rapidly around the globe, not only within one country, and cause hundred of millions, of not billions, of fellow humans to die.

6. Prevention and Preparedness is Essential in Public Health

There are a number of medical and ethical issues which need to be discussed in detail as means of prevention and preparedness. Traditional measures in public health already have caused controversy among bioethicists and suspicion in certain populations. Polio vaccination in Nigeria has met resistance by strong forces in traditional culture and was introduced by poor government education programs. But vaccination programs as a means of prevention for diphtheria, tetanus, whooping cough, meningitis, flu, measles, mumps, rubella, hepatitis A, and influenza are either mandatory for certain risk groups or offered to highly vulnerable people. Immunization is a service to the individual as well as to the community. Education in how to prevent the spread of disease or to reduce the risk of occupational or lifestyle related accidents also are important features in the protection of health for the individual as well as the community.

Preparedness for biomedical disasters of mass proportions includes not only training of health care professionals; cooperation with other local experts and public authorities is essential. Material has to be pre-positioned, facilities other than hospitals have to be determined as shelters or for quarantine. Health care workers and other disaster relief personnel have to immunized preventively, if and when a specific bacterial or viral pathogen infection or attack cannot be excluded. Such immunization programs are costly and also might have side-effects on the health of those immunized. Ethical and professional issues associated with mandatory preventive immunization programs need to be addressed prior to immunization. Some health care workers will be quarantined

together with patients; those who for a variety of personal or family reasons rather should or would not be quarantined need to be identified long before and formal quality criteria for selection need to be developed and publicly and professionally discussed prior to implementation.

Prevention, whenever and wherever possible, is important to reduce dangers, once they cannot be avoided or averted. Prevention methods include immunization programs, education of citizens to be vigilant and alert, to follow safety recommendations and instructions. Another means to reduce the severity of a catastrophe is appropriate training and rehearsal, in particular, when many parties on the local level are involved. The chain of command needs to be established in such realistic training programs. Also material needs to be ready and pre-positioned, so that it is readily available where it is needed.

Additional to natural catastrophes, the same measures of prevention and preparedness need to be applied to the possibility of man-made disasters, those by accident and in particular those caused intentionally. Given the immoral and criminal intentions of a few determined criminals to kill innocent civilians, it also cannot be excluded that they will find neurotic or criminal expert to help them to specifically engineer deadly pathogens just for the purpose of killing fellow humans. It has been discussed to, in particular, to limit information and scientific publication on molecular research knowledge of manipulating pathogens, as such knowledge can be used by criminals to construct even more deadly viruses or bacteria. While the dissemination of knowledge rarely can be suppressed for longer periods of time, patents cannot be granted and further research will be hampered, including research on developing vaccines and antibodies for rapidly changing pathogens, as the recent H5N1 flu virus seems to be.

As disaster management is service to the people under extraordinary circumstances, public officials and health care providers need to prepare themselves during normal times for extraordinary times. Therefore rehearsals and planning and implementation exercises are extremely important. It is essential to determine the chain of command, to have more than one means of communication, to preposition materials and goods, also to include the private market sector. Bioethicists Childress, Kipnis and Moreno speak about a 'publicly accountable system' in which the public trust and the protection of the community are of highest priority; Kipnis outlines a 'decentralized system of health care delivery under catastrophic conditions, health care without hospitals' [Moreno 2004:xxi, 95ff].

Private market businesses such as supermarkets, hardware stores, hotels offer special routine service to the people; they are profit oriented and have experience to change services and goods depending on demand. The profit motivation and the skills of private business should not be underestimated in contributing to manage big and unexpected crises and disasters. In particular, when natural disasters can be foreseen, private business will preposition goods and services and might be quicker in a response to mass calamities, as has been shown in relief efforts for hurricane victims. It would be prudent for public officials in control of disaster relief to not also micro-manage the private sector, rather encourage the private sector to cooperate in relief efforts, whenever possible. The Daoist saying 'you win the world by letting alone' can be translated for government officials into the emergency situation when not everything can be done by public officials and actually should not be done by public officials and response teams. There is a certain prudence in competitive market forces, where people know their skills and are compassionate, that they as citizens and as

professionals will help where they feel help is needed and can be provided by them. Thus, the encouragement of civil ethics, i.e. the ethics of citizenship and neighborly love, is one of the most important tasks of public officials and of public discourse and culture.

7. Hard Cases in Public Health and in Great Danger

There are some 'hard cases' which had been discussed in the bioethics literature and unfortunately are occurring again and again. I mention just three: (1) Investigational torture of terrorists in order to gain information which could save hundreds, thousands or millions from attack and death; (2) killing out of compassion and mercy; (3) saving the life of an enemy in situations of limited resources.

(1) Investigational torture. *The case: A terrorist was captured who very likely has information on the whereabouts of other members of his team, his superiors and of plans of immanent attacks on a high number of people. The captors ask you to assist and consult as medical expert in proceedings of torture as a means of last resort to save very many innocent people in immediate danger. What would you do?* Possible benefits are evident and include the saving of highest numbers of innocent people, work as a disincentive for potential criminals and could lead to capture of other criminals. The World Medical Organization in 1982, and again in 2004, passed a resolution that 'medical ethics during armed conflict are identical to those in peacetime'.

(2) Mercy-killing. *The case: After a car accident, a triage situation develops and the most severely hurt cannot be treated; they scream in extreme pain and agony; some ask to be killed. They know and everyone else knows that they cannot be saved and that all of them will die a painful death. Would you active kill those who plea for that, would you also kill the others who are in similar agony but only scream?* Situations like this have been reported from the battlefields of the past when wounded soldiers were screaming between enemy lines with no hope to salvage them. In some cases, their soldier friends shot them, in other cases they listened to the screams of their comrades for hours and hours. Mercy-killing is an issue which does not occur only in warlike situations; it is an everyday issue in treating terminal patients who are in pain and suffering. Professional codes of conduct in Western as well as in Chinese medicine refuse vehemently the active killing of a fellow human as contrary to the rules of ethics and nature, and the obligations of physicians; but there are situations where compassionate health care professionals and family members have resorted to killing patients or their loved ones out of mercy and compassion.

(3) Costly health care for an enemy. *The case: United States Special Forces capture a combatant in Eastern Afghanistan, only to find out that he needs dialysis treatment. The prisoner refuses the treatment, saying he would rather be dead than in the hands of the enemy. Doctors are reluctant to treat without informed consent. Two days later, the US Secretary of Defense orders dialysis treatment, arguing that the prisoner might have valuable information on other terrorists and on planned attacks. What would you have done?* [Zupan et al 2004] The Geneva Convention on treating prisoners of war requires equal and fair treatment to all, prohibits medical experiments on prisoners if those are against the prisoner's interests, and requests informed consent.

There are more than these three cases to which an answer is not easily found and in regard to which bioethicists, health care professionals, public officials, and each and everyone of us might have different opinions. Research literature in bioethics documents and reflects these different opinions. Hard cases rarely can be solved in the classroom and should not be solved in the classroom by giving instructions, such as

you would give instruction in a cookbook or for standard treatment in medical care following quality norms. These are cases of a very personal matter where ethical and medical analysis is not enough to make decisions or to criticize decisions. The moral agent to make those decisions, beyond the capability of moral calculation, is the person in the actual situation. *Only in an actual situation, the interaction and combination of expertise and ethics can be the final test for professional and compassionate behavior based in personal responsibility.* Decisions might be right or might be wrong; one might regret to have made a certain decision at a later date. One might regret not to have involved oneself in interrogational torture because it became evident that 1000 lives could have saved, if one had not refused.

8. Disaster Ethics Is Partnership Ethics: Serve the People

Reviewing extraordinary situations of challenge to physician's and health care expert's professionalism and compassion and addressing hard cases, for which there is no clear-cut answer, points to the different roles and obligations and duties for health care professionals: Some in the field of public health, some in consulting or treating the individual patient, some in consulting on prevention, some in accompanying and comforting the frail and dement, some in consulting public officials, some in being elected to a public office based on skills and knowledge as an expert in the care for health. High-tech cultures depend essentially on skills and compassion of experts, individual citizens and communities. Physicians and other health care workers play many roles in modern society: treating patients in acute and in chronic situations, consulting and advising citizens in regard to lifestyle, nutrition, occupational and environmental health, researching and improving family and clinical medicine and epidemiology, advising government and corporations in regard to safety and reduction of risk to health, preparing, advising and cooperating in the management of natural disaster, epidemics, biomedical terror and warfare. *Dr. Research, Dr. Acute, Dr Consult, Dr Care, Dr. Manage, Dr Prepare, Dr Govern, Dr Teach, Dr Partner, Dr Special, Dr Example, they all display special skills in their craft. But all these different skills need to be developed and cultivated in the tradition of the good doctor, who according to Confucian physician Yang Chuan (300AD) defined a set of interactive professional virtues for the physician, who combine skills [ji] with compassion [ren], who are clever and wise, sincere and honest.*

Whether treating patients in the family medicine or in high-tech medicine, in disasters, epidemics, or in war, physicians need to cooperate with others, with people who organize emergency logistics, who understand radiation, pathogens or earthquakes, who can coordinate and manage. But above all, it will depend on the compassion and team spirit, all these people bring together with their skills. Real situations are different from simulated situations. But anticipatory simulation and preparedness allows for better managing extreme situations. Discussing the extreme challenges of crisis ethics, triage, epidemics, and biomedical terror and warfare in the classroom or in preparation meetings results not in a protocol that produces moral solutions, but those discussions and actions 'enhance awareness of the many moral aspects of the daily practice in which professionals operate'. What the classroom discussion in medical ethics, in public health ethics and in the ethics of emergency care cannot do, is to prescribe a list of 'to do' and 'do not'. But case studies and analytical evaluation of medical and moral options can help to develop what has been called 'moral competence': 'the ability to see what is morally relevant in a situation, knowing the points of view from which one sees it, understanding that others may see it differently, and then, with others, responding well to

what one sees' [Verkerk 2004:37]. Classroom teaching is easy; life is not easy; making ethical decisions in exceptional situations is not easy. Easy to understand is the obligation to safe life, to alleviate pain and to professionally consult in matters of a healthy lifestyle and the enhancement of life; difficult is the implementation of all of this.

Extreme situations require extreme, sometimes very unpleasant and very extraordinary means of protecting individual lives, families, neighborhoods and communities. Those extraordinary means need to be guided by principle and prudence, strategically coordinated, and executed with skill and compassion. Preparedness pays off as it reduces calamities and makes the community stronger; also surviving disasters makes individuals, communities, institutions and corporations stronger.

[A lecture delivered in October 2005 at Peking Union Medical College and Tsinghua University, Beijing]

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News in Bioethics & Biotechnology

<http://www2.unescobkk.org/eubios/NBB.htm>

News will appear in the January 2006 of *EJAIB*.

International Bioethics Education Project News

<<http://groups.yahoo.com/group/Bioethicseducation/>>

IAB Genetics & Bioethics Network: On-line

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<http://www2.unescobkk.org/eubios/ABA.htm>

Conferences

A list of conferences will appear in the November 2005 issue. Another bioethics conference calendar website is:

<http://www.who.int/ethics/events/en/>

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Editorial address:

Prof. Darryl Macer

RUSHSAP, UNESCO Bangkok,

920 Sukhumvit Rd, Prakanong,

Bangkok 10110, THAILAND

Fax: Int+66-2-664-3772

Email: asianbioethics@yahoo.co.nz

d.macer@unescobkk.org

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