

THE CHURCH IN SOCIETY COMMITTEE

MEMBERSHIP

The Bishop of Clogher, The Rt Rev Dr MGStA Jackson (Chairman)
The Archbishop of Armagh, The Most Rev Dr RHA Eames
The Archbishop of Dublin, The Most Rev Dr JRW Neill
Rev Canon Dr IM Ellis (Honorary Secretaries' nominee)
Dr R Corbett (Medical Ethics Panel)
Rev KRJ Hall (Social Justice and Theology (NI) Sub-Committee) (Elected by Standing Committee November 2005)
Mr SR Harper (Legislation and Politics (RI)) Sub-Committee (Honorary Secretaries' nominee)
Rev WD Humphries (Environmental and Ecological Panel) (Elected by Standing Committee November 2005)
Rev Canon WA Lewis (Legislation and Politics NI Panel)
Lord Maginnis of Drumglass (Social Justice and Theology (NI) Sub-Committee)
Ms S Mew (Environmental and Ecological Panel) (resigned November 2005)
Dr K Milne (European Affairs Working Group)
Very Reverend FJG Wynne (Social Justice and Theology (RI) Sub-Committee)

OBJECTIVES

1. The Church in Society Committee of the General Synod of the Church of Ireland seeks to identify, contribute to, challenge and develop areas of living today where the mission of the church can be active and the love of God shared. It does this through the development of reports, resource materials and by developing projects that apply theological perspectives to public issues in a challenge to Christian living.
2. This year's major projects included:-
 - Establishing and supporting the Eco-Congregation Ireland project and promoting good ecological practice in parishes.
 - Publishing and promoting the *Go and do likewise* report.
 - Maintaining dialogue with the political groups in Northern Ireland
 - Preparing responses to consultations and legislation. The following were prepared: Submission to the Department of Justice, Equality and Law Reform on the proposed *Immigration and Residence Legislation* in the Republic; Response to the Office of the First Minister and Deputy First Minister on their *Services for Victims and Survivors* Consultation; Response to the Department of Trade and Industry Consultation on *Work and Families: Choice and Flexibility*. The Chairman formed part of a group which attended a briefing on the *Northern Ireland Offences Bill* ('On the Runs') and raised certain objections in relation to criminal, civil and social justice issues and the rights of victims. However, the legislation was withdrawn subsequently and no further action was required.

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- Contributing to the dialogue between the institutions in Brussels and the churches.
- Preparing statements on medical ethics issues: *Issues on Drug Research in the Third World*.

COMMITTEE REPORTS

SOCIAL JUSTICE AND THEOLOGY (RI) SUB-COMMITTEE

1. **Local Partnerships:** Text of a booklet to inform the Church on partnerships whereby the statutory agencies and the voluntary principle combine to provide social care is being prepared for publication. This will be a companion booklet for the Northern Ireland publication *Go and do likewise*.
2. **International Community:** Work is being done in conjunction with the Dublin & Glendalough Diocesan Committee for the International Community, mainly to enable the latter's output to reach a national audience and to give it authentication by the Church in Society Committee. Submission made to the Department of Justice, Equality and Law Reform on proposed *Immigration and Residency* legislation. A handbook is being prepared for the Church on the whole question of welcoming and integrating with new people from abroad. Use will be made of the November 2005 conference on racism at Dromantine.
3. **Resurgent Nationalism:** The new wave of political and other fundamentalism is a serious challenge to the church across Europe and more widely. Draft information paper under consideration.
4. **Forum on Child Poverty:** The Chairperson attended a conference in Dromantine in December 2005. Work is ongoing to develop the work begun at this meeting.
5. **Glenstal Ecumenical Conference:** The Chairperson invited to give a paper in June 2006.

SOCIAL JUSTICE AND THEOLOGY (NI) SUB-COMMITTEE

The sub-committee prepared a number of responses to consultation and legislative documents. A submission was made to the Department of Trade and Industry on *Work and Families: Choice and Flexibility*. This was approved by Standing Committee and is attached as an appendix to their report. Another response was formulated for the Office of the First Minister and Deputy First Minister regarding their consultation document on *Services for Victims and Survivors* (see Appendix A).

A booklet by Rev Canon David McClay entitled *Go and do likewise* was published by Church House Publishing. It aims to provide parishes and clergy with the resources to engage with local communities and develop social outreach programmes. The booklet was launched on 27th October 2005 in Church House, Belfast, and circulated to all clergy throughout Northern Ireland.

EUROPEAN AFFAIRS WORKING GROUP

Executive Summary

The European scene has been dominated for the past year by the fate of the proposed Constitutional Treaty that was rejected by the electorates of France and the Netherlands, creating a situation of great uncertainty as to the future development of the European Union. We have followed the course of these events as closely as possible, particularly through participation in discussions in Brussels under the auspices of the Church and Society Commission of the Conference of European Churches and by means of our membership of the National Forum on Europe and the Institute for European Affairs in Dublin.

The Constitutional Treaty

Following the rejection of the treaty by two member states, the Union initiated a 'period of reflection', on the future of the continent and on what steps might most appropriately be taken to achieve the objectives of the treaty, prominent among which were a consolidation of a great mass of EU regulations that had accrued over the years, and modifying procedures to allow for the efficient conduct of a greatly-enlarged Union. Particularly on the part of the churches, there is a strong desire to ensure the survival of the Charter of Fundamental Rights and implementation of the undertaking provided for in the treaty to establish regular consultation between the agencies of the Union and the churches.

National Forum on Europe

The Irish government has looked to the National Forum on Europe (of whose Special Observer Pillar the Church of Ireland is a member) to promote this reflection among the citizens of the Republic. The Forum is hoping to engage more fully with the component parts of civil society, such as the churches and, in response to an invitation, we are considering possible ways in which appropriate structures within the Church might co-operate in this exercise. The Forum invited submissions on issues facing Europe, especially related to enlargement, the social model, globalisation, and the environment, and copy of our submission is appended. (see Appendix B).

MEPs

As reported last year, we met with a cross-party group of MEPs in Dublin last year. We have already met with one MEP from Northern Ireland at the Commission Office in Belfast, and have sought meetings with the others.

Institute for European Affairs

The Institute of European Affairs in Dublin continues to provide a very full programme of lectures and seminars, which explore issues including those relating to enlargement, usually with the participation of representatives of the new member states or candidate

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states. Turkey's candidature is a particularly controversial one, as was clear from the debate on our report at last year's session of the General Synod and the Institute has been addressed by the President of Turkey.

Peace and Neutrality Alliance (PANA)

At their request, the working group met with members of the Peace and Neutrality Alliance.

MEDICAL ETHICS, SCIENCE AND TECHNOLOGY SUB-COMMITTEE

The sub-committee has completed the report on Drug Testing in the Third World (attached as Appendix C).

A meeting was held with representatives of the Irish Heart and Lung Transplant Association following a request made at Synod. This was very satisfactory and we were able to reassure them that we were all very much on the same side in our desires to see more operations carried out. In particular there was a discussion as to whether there was an active role that could be played by the Church over and above the present pastoral role. It was felt that this was perhaps not yet appropriate.

The Chairperson held an exploratory meeting with Mr Robert Cochran, Secretary of the Methodist Council of Social Responsibility in the Republic, and we are agreed that there are many issues that we have in common and will be meeting in the future to discuss possible joint ventures.

There is a group looking at the issue of the ethics of the Medical and Social Care of the Elderly in our societies, but is not yet ready to report.

ECOLOGICAL AND ENVIRONMENTAL SUB-COMMITTEE

Over the past year, the Ecological and Environmental sub-committee has overseen the establishment of Eco-Congregation Ireland, an environmental project that aims at encouraging good ecological practice within parishes. Adapted from the original scheme set up by Churches Together in Britain and Ireland (CTBI) and Environmental Campaigns (ENCAMS), modules have been tailored to suit Irish needs. The website www.ecocongregationireland.org provides free downloadable resources and support for all churches that sign up to the scheme. Ecumenically run in conjunction with the Methodist Church in Ireland, the Presbyterian Church in Ireland and the Roman Catholic Church, the Eco-Congregation Ireland project received generous funding from the Irish Inter Church Meeting. We would like to take this opportunity to thank the IICM for all their support in helping us to raise awareness of this most important area of mission.

The sub-committee also received during the year the resignation of Ms Stella Mew as chairperson. Ms Mew was fundamental in the development of the Eco-Congregation Ireland scheme and her enthusiasm and dedication will be missed.

LEGISLATION AND POLITICS SUB-COMMITTEE (NI)

The sub-committee's work has been clearly set in the context of meetings with political parties - the parties briefing the committee on policy and practice, and the committee responding and presenting its thinking. In general, the engagements have been mutually informative and beneficial.

However, 2005 was a difficult year for the work of the committee. Several matters, including the repercussions of the Northern Bank robbery in December 2004, attributed to the Provisional IRA in the Independent Monitoring Commission Report (10th February 2005), were the cause of considerable concern among the membership. Whatever trust had existed in relation to Sinn Fein was severely damaged. That begged the question of the usefulness of discussions with Sinn Fein. However, the committee remains committed to continuing effective dialogue.

While pressures of time did not allow us to meet all political parties, during the year meetings were held with the SDLP and the DUP. A meeting with the UUP is planned. The SDLP outlined their commitment to opposing Loyalist and Republican criminality, and its morally and ethically corrosive effects on society. They also highlighted the importance of the need for full support for the PSNI by all the political parties; and the transparent commitment by Sinn Fein to exclusively peaceful means. The committee encouraged the SDLP in its positive and principled leadership.

At a meeting in November 2005, the DUP expressed the view that there would not be devolved government in Northern Ireland for at least two years. The party, they said, is committed to power-sharing in a local Assembly with parties which are fully democratic. Hence the importance of transparent and verifiable decommissioning. The committee encouraged the DUP to use its position as the largest Northern Ireland political party to exercise its leadership in promoting justice for all, and in advocating the cause of the vulnerable and marginalized.

In its work over the last year, the committee has found the Reports of the Independent Monitoring Commission helpful and significant in providing authoritative information. It recognises the importance of the Commission's work in bringing fundamental issues such as paramilitary criminality, political intelligence-gathering, and the abuse of restorative justice into the public arena, enabling the community to express its rejection of these ethically unacceptable practices in a democratic and inclusive society.

Such matters demand vigilance and remedial action as the Church seeks to serve the Kingdom of God in our society, through the affirmation and advancement of the positive values of truth, justice, integrity and love.

LEGISLATION AND POLITICS SUB-COMMITTEE (RI)

We continue to monitor proposed legislation. Following our submission and oral presentation to the All-Party Oireachtas Committee on the Constitution (APOCC) on The Family last year, members of the sub-committee attended the launch of the APOCC's *Tenth Progress Report* in January 2006. Review of this report is ongoing.

The Chairperson attended a seminar by Law Reform Commission on the *Rights and Duties of Cohabitees* held in January where there was an opportunity to reiterate the points made in the committee's original submission. Mrs Judith Peters of the Pensions Board was in attendance also.

Contact is being maintained with the both the Department of Social Welfare and the Department of Justice with a view to monitoring regulations that are being brought in regarding social welfare payments to unmarried mothers and provisions for cohabitees.

APPENDIX A

SERVICES FOR VICTIMS AND SURVIVORS

OFFICE OF THE FIRST MINISTER AND DEPUTY FIRST MINISTER

Response

Social Justice & Theology (NI) Sub-committee

1. A clearer vision for the healing of victims is needed in this document.

Healing is enabling victims to move from victim, to survivor, to victor over their trauma. This will be assisted by the context of a peaceful society which can openly recognise all suffering of the past, has dealt with the past justly, and is free from the acts of violence or threat of cross community strife.

Reconciliation and good community relations are intrinsic to the healing of victims. It is hoped that the statement of the changing needs of victims will encompass the need for reconciliation, although that may seem too much to make explicit now.

However there should be more detail given to the kind of society we wish to work for. This will give grounds for hope, which is fundamental for all working in this area.

- 2 *'victims should be afforded dignity and respect It was also stressed that service delivery needs to be clearly focussed on achieving specific results in a targeted manner within available resources and that services should be co-ordinated in a consistent and effective manner between the relevant statutory, community and voluntary sectors.'* (page 4)

This quote from the document exemplifies the inherent tension in providing services for victims; the needs of providers to put in place accountable services, and the needs of

victims and the services they would demand. Part of healing for victims will include the sense of being heard, and compassionate responses being made to their needs.

However the needs of victims may extend beyond their current felt needs. This is an extremely delicate point, for victims need to be accepted where they are. But also if healing is to take place, they will not stay where they are. There is a need to deal with the past, to gain freedom from the life inhibiting effects of trauma etc. However there is also a need to gain a vision of a future, which is possible to achieve, where the past is dealt with adequately, and where the poison of their experience will cease to influence their quality of life.

So we welcome the statement:

‘Over time needs change and it is considered important that the strategy looks forward and ensures that work with victims and survivors does not become locked in time, but plays a part in promoting a more sharing and less divided society in future.’ (page 7)

Envisioning a shared future needs to be intrinsic to the services provided for victims.

3. Victimhood

Healing will mean leaving behind a culture of victimhood whereby a person’s identity is strengthened by being a ‘victim’ and where those who are ‘to blame’ for their victimhood are categorised as those who must change.

Those locked in victimhood find the recognition of ‘all victims’ intolerable. To such the ‘other so - called victims’ aren’t worthy of the name victim. This is recognised briefly in the aspiration on page four *‘where the suffering of all victims is recognised’*, where victimhood as such can disempower people as they are likely to insist that ‘others’ have the moral obligation (and therefore the power) to put things right. This attitude means that those who feel themselves victim are yet again victimised as powerless. The move from blaming others, to taking action to address your needs and fulfil your aspirations, is intrinsic to the rehabilitation of victims as active citizens and agents for positive change within civil society. To fail to accept this vision for victims is to diminish their rights for healing.

It should also be recognised that victimhood also affects communities where they feel they are suffering because of another community.

4. Victims’ Groups

It is recognised that great work has been done by victims’ groups. It is essential that services to victims should involve the work of victims’ groups. However one of the difficulties in relating to victims’ groups as service providers for the healing of victims, is that to belong, to avail of the services, you are a victim. This can reinforce the victim culture.

Also, there are individuals who do not wish to be part of a victims’ group. Support for these individuals would be best mediated through **trained and accredited volunteer victim support workers** (see below).

5a. Healing, Peace and Reconciliation

The recognition of all victims is difficult while inter-community tension prevails and reconciliation is not being addressed. Healing of inter-community mistrust is central for the healing of victims. It is accepted that reconciliation may not be able to be addressed at an early stage in the healing of victims, however it must be recognised that a sense of wholeness will not be possible unless issues of reconciliation are addressed.

Recovery from victimhood demands great change for that person, and will also require a change in their context. Good community relations, skills in dealing positively with difference, respecting the identity of others and, in turn, having one's own identity respected, is all part of what it means to move beyond victimhood.

This means that a wide group of resources are appropriate to the welfare of victims which may not normally be associated with the 'victims' groups'. As well as the service providers mentioned you should also include those working for cross community reconciliation, community relations, inter-church work etc.

5b. Healing and Political Progress

There is a deep mistrust on the part of some victims of statutory services. There is a fear that the needs of victims are being addressed in order to remove them as an obstacle to 'political progress' rather than a genuine concern for the injustice they have suffered.

It is not appropriate to demand that victims should bear the responsibility for the difficult process of negotiating peace. While not excluding their views, they cannot be expected to bear the pain of such costly work. However careful attention and public recognition must be given to the pain caused to victims by necessary actions to promote political progress.

5c. Healing and Hope

There needs to be an exploration by victims and service providers of the kind of society the victims' services are working towards, the values they aspire to, and the quality of relationships between constituent groups they are working to create.

The wider context of a peaceful society is directly related to healing for victims. Otherwise continuing violence means that hope is eroded and wounds are opened by the recurrence of similar events. Envisioning such a society is a step to achieving it.

Proposals

1. **Good relations** should be part of the vision of the context necessary for the healing of victims. This should be one of the programme streams which will attract funding by those groups providing services or programmes for victims and victims' groups.

The importance of community relations to the healing of victims is illustrated by the experience of victims meeting within a cross community context. The sharing of stories within one's own community has been shown to be helpful but also across community boundaries it is extremely important and illustrates a element

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of reconciliation, of having one's story heard and received by the 'other' community from which the perpetrator is perceived to have come. This is a means of addressing both the personal and community orientated aspects of the healing of victimhood.

2. **Diversity of victims' groups:** Victims' groups should be encouraged and should aspire to be inclusive of diversity in the victims they identify with and support.
3. **Collaboration of victims' groups.** Victims' groups are key deliverers of appropriate services and programmes for their members. However to enable their members to move beyond victimhood, they may need the collaboration of other groups. So the building of networks within and beyond the victim community is extremely important.

Where possible the promotion of cross community victims' groups should be explored, since the healing of victims must include the healing of their relationship with that community which is perceived to have caused their suffering.

4. **Importance of cross community membership of Trauma Advisory Panels (TAPs)**
The cross-sector and cross community aspects of TAPS are very valuable. Much of what is stated above should provide the modus operandi for TAPs
5. **Should roles, functions and criteria for membership of TAPs be set out in legislation?**
Legislation won't drive the work for victims. Commitment to this work and accountability to others working in the sector are of more importance. As is acknowledged, victims work will progress over time and therefore unforeseen changes in the role and functioning of TAPs may be necessary. However it is essential to maintain the cross community aspect of TAPs membership.
6. **Users and carers groups involvement**
The formation of a Users and Carers Reference Panel should be established under the Commissioner. Representatives of this panel should sit on all the committees responsible for victims services, not only the TAPs but **including the Interdepartmental Working Group (IDWG)**. Otherwise the agenda will be driven by the department's needs or the committee's agenda rather than the needs of the victims. What is said and decisions that are made is influenced hugely by 'who is in the room.' To maximise the effectiveness of the victims' services provided, victims must be 'in the room'. Not least the involvement of victims at every level is essential to building trust through openness and transparency of the procedures.

- 7. Communication including the voluntary sector, churches etc.**
Concern for victims pervades a very large proportion of the voluntary and community sector, and indeed of statutory services as well. Individuals within such organisations should be designated as responsible for the communication of victims' issues. They could be update by e-mail from the office of the Commissioner for Victims and Survivors. This is in addition to the Victims and Survivors Advisor in each HSS Board area and TAP co-ordinator.
- 8. Victims and Survivors Advisors** should not be half time as liaising with the community and victims' issues would be most useful. However these advisors should be supplemented with **accredited volunteers**.
- 9. Accredited training for volunteers**
As stated above there is mistrust by some victims of statutory services. Also some victims are not comfortable associating with victims' groups.
An accredited training scheme for volunteers to work with victims should be established. These volunteers could provide information, support, and guidance for victims. Within the voluntary sector there are many skilled volunteers within other organisations and community groups who, with additional training, could be a valuable asset in the healing of victims; Victim Support, mental health charities, local counselling services, clergy, etc. Key to this is the central accreditation and the quality of the training and supervision of such volunteers.
Accredited volunteers should work ultimately under the Commissioner (through appropriate structures) to give legitimacy for their role and credibility with victims.
- 10. Commissioner for Victims and Survivors**
This role should include the oversight of the IDWG, TAPs, the Victims and Survivors Advisors and the accreditation of volunteers.
This role is an excellent suggestion. However the effectiveness of such a Commissioner, and ultimately the value of all services being discussed, will depend upon the credibility and respect in which the Commissioner is held.

Prepared by: **Rev Canon TR Williams**
Very Rev RC Thompson

APPENDIX B

SUBMISSION TO THE NATIONAL FORUM ON EUROPE

Church in Society Committee Working Group on Europe

1. The EU is in some measure the victim of its own success. Many citizens appear to take for granted an unprecedented situation whereby for half a century Western Europe has been spared the horrors of war. The ease with which citizens can move freely across the continent, residing and working in countries other than their own, is assumed, particularly by the young, to be nothing out of the ordinary. Therefore, the *raison d'être* of the community, as enunciated by its founding fathers, has been largely lost sight of, as freedom of movement across the continent and open labour markets are so much taken for granted.
2. But the history of Europe over the centuries provides ample evidence to show that progress towards peace and prosperity is neither inexorable nor irreversible. Therefore, we believe that strenuous efforts must be made by governments to point out that the dangers facing the continent today are as great as ever, and that the existence of a community of nations, such as the EU, is vital if present conditions of peace and relative prosperity are to be sustained.
3. Irish enthusiasm for the union, as for the community that preceded it, has owed much to the tangible economic and social benefits that so clearly accrued from membership. Before long, however, Ireland will be a net contributor, and it is vitally important that its citizens are brought to realise that they now have an obligation to assist with the development of new member states as they themselves were helped (and are still being helped). But there are other major considerations to be borne in mind.
4. The significance of the EU as a community of values needs constantly to be declared. Hence the importance of the Charter of Fundamental Rights, the purpose of which, as a protection against infringement of citizens' rights by EU legislation, is frequently misunderstood. Comparisons with the empires of the past are wide of the mark, for this is a voluntary coming-together of sovereign states who have pooled their sovereignty in the interests of the common good. Any member can leave, if so inclined.
5. Many major challenges face the modern world, and they are linked to one another. Human rights, globalization, immigration, development aid and care for the environment are interrelated. While it is essential that individual states (and indeed individual citizens) should address these concerns with energy, it is inconceivable that this can be done effectively without international co-operation, and the EU is extremely active in these spheres. Furthermore, while a variety of social models exists within the Union, a 'European model' can be discerned, common to them all,

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which attempts to balance matters of social justice with those of economics in a manner that is far from universal on other continents.

6. We understand the concerns of those who fear for the future of Ireland's traditional, if not always clearly defined, policy of neutrality. But we are certain that it would be morally indefensible for any member state to refuse responsibility for the safety of its fellow-members. We suggest that, just as the political and economic climates that motivated the founding fathers of the community have changed, so too, perhaps, has the situation in which Ireland first enunciated its stance on neutrality and alignment. The time may well have come for a national debate in the Republic on the meaning and purpose of neutrality today.
7. As it has been widely acknowledged that the EU must engage more efficiently with its citizens, we would hope that the institutions will move to establish the 'open' and 'regular' dialogue with the churches that was provided for in the Treaty, despite the uncertainty surrounding the future of the Treaty. We appreciate the fact that the Irish government is taking steps to establish such procedures nationally in the Republic.

December 2005

APPENDIX C

ISSUES OF DRUG RESEARCH IN THE THIRD WORLD.

Medical Ethics, Science and Technology Sub-Committee

"I was hearing of the frantic recruitment of third world 'volunteers' as cheap guinea pigs. Their role, though they may not ever know this, is to test drugs, not yet approved for testing in the US, which they themselves will never be able to afford even if the tests turn out reasonably safe. -- John le Carre¹

Summary.

Multinational pharmaceutical companies stand accused of exploiting poverty in the developing world by failing to give priority to the development of drugs and vaccines needed by the poor (e.g. antimalarial drugs) because there is no profit in it; by preventing

¹ www.heureka.clara.net/gaia/pharmas.htm

the manufacture and import of cheap generic drugs, by unethical use of the poor in drug trials, and by engaging in biopiracy².

Key Issues.

Only 1% of new medicines brought to market by multinational drug companies between 1975 and 1997 were designed to treat the tropical diseases that kill millions in the Third World³. Clinical trials of drugs and vaccines intended for poverty-related diseases such as malaria, tuberculosis and HIV/AIDS in developing countries under E.U. partnership programmes are commended as ethical, nevertheless, they require very strict control where documentation and clinical practice is less sophisticated. Elsewhere, medical trials involving HIV/AIDS attract heavy criticism⁴, because this is a very vulnerable group, keen to have treatment which is not otherwise affordable. Women are particularly vulnerable, and in one trial to prevent transmission of HIV/AIDS to children, they were given a placebo despite the fact that the drug AZT is already known to stop infection⁵. The defence would be that the priority is to developing cheap medication to stem the explosion of the disease in developing countries, and that maintaining placebo groups will increase the speed and effectiveness of the tests. If the right treatment can be developed quickly, they argue, hundreds of thousands of lives can be spared in the future. While it is regrettable that some women and their children must be consigned to a placebo group, they say, the overall benefit will outweigh this sacrifice.

While Western medicine might be attuned “hit and run” trials, the absence of sustainability and relationship exhibited in such research enhances denigration of rich nations in the eyes of peoples oppressed by a patronising culture of dependency and exploitation.

In the USA the average cost of a clinical trial is \$10,000 per patient, in Russia it is \$3,000. Figures are not available for underdeveloped countries, but it is probably much less. It can take \$800 million to bring a new medicine to market, and thus the risk of exploitation is high. Insurance overheads are much less or non-existent in poor countries. Foreign drug trials have rapidly increased in Eastern Europe, Latin America and in Russia, where ethics review boards often are inexperienced and unsure of their roles. The

2 The charge by Third World countries that the multinational drug industry has “pirated” several billions worth of intellectual property in the form of plant-based traditional remedies from Africa, Asia and Latin America, has yet to be answered. And that “pirating” continues. It is important to state that the Paris Convention, an international agreement adopted in 1883 and revised six times and still in force, clearly states that non-protection of pharmaceutical patents is perfectly acceptable.

3 Doctors Without Borders.

4 Public Citizen, The US medical consumer group

5 Tuskegee Experiment. a “textbook example of unethical research” conducted between 1932 and 1972: the Tuskegee Study of Untreated Syphilis. During the course of those infamous tests, 412 poor black farmers in Alabama were left untreated by government researchers -- even after penicillin, an effective treatment for syphilis, was discovered. New England Journal of Medicine published a much discussed editorial strongly criticizing a series of federally funded AIDS tests in developing countries. The editorial, by Dr. Marcia Angell, made the case that the studies constitute an unacceptable breach of medical ethics because they abandon those subjects in the “placebo group” to contend with untreated illness.

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FDA is unable to ensure that trial participants receive the same level of protection as those in the United States, and foreign Regulators cannot be relied upon to make sure patients are fully informed of risks and sign up willingly. There is the danger in extrapolating results from samples in a non-industrialised, poor environment to rich industrialised nations. There is the problem of extrapolating results from a different genetic pool.

The balance of bringing new drugs to market quickly to help people in need, and doing good science to protect the public from a drug's potentially dangerous side effects has been well rehearsed in systems such as the complex and elaborate Federal Drug Administration procedures. Such systems are poorly developed in poorer nations. Where health systems fail to meet demand, pharmaceutical trials can enhance care through provision of drugs, training, organization, buildings and equipment. But doctors and the sponsors of clinical trials, who include university departments as well as drug companies, say the changes needed to enhance provision cause research to become too expensive, and too onerous to continue after the study. Distinguished scientists agree with pharmaceutical companies that guidelines requiring researchers to provide the best proven treatment presents problems where demand exceeds provision. If interpreted literally, ethical guidelines to provide adequate levels of provision would make it almost impossible to do research.

The World Medical Association (WMA) has asked pharmaceutical companies to ensure clinical trials are carried out to the highest standards. Amendments to the Declaration of Helsinki⁶ have prioritised protection of participants in clinical trials in that participants must be fully informed of the risks and must be given proper medical care. UNAIDS has called for trials to be independently monitored to ensure they meet ethical standards. Amendments ask that patients who take part in a trial get the best treatment for their medical condition once the tests are over. The practicalities of this prove very difficult where health systems are rudimentary⁷, and are impossible unless approved by the authorities in the host country. In the UK or USA patients in clinical trials continue to get successful new drugs on a compassionate basis after a study has ended, and before the granting of a licence.

Technological innovations are not "neutral"; they embody the values of their creators and sponsors. Billions of dollars are spent every year on weapons of destruction and luxury goods, consumerism rides high in the list of features of post-modern society. Technologies that would dramatically improve the quality of life in poor countries, such as nonpolluting energy sources, sustainable agricultural systems, basic health and

⁶ World Medical Association Declaration of Helsinki; Ethical Principles for Medical Research Involving Human Subjects. Adopted by the 18th WMA General Assembly, Helsinki, Finland, June 1964, and amended by the 29th WMA General Assembly, Tokyo, Japan, October 1975, 35th WMA General Assembly, Venice, Italy, October 1983, 41st WMA General Assembly, Hong Kong, September 1989, 48th WMA General Assembly, Somerset West, Republic of South Africa, October 1996, and the 52nd WMA General Assembly, Edinburgh, Scotland, October 2000, with notes of clarification on Paragraph 29 added by the WMA General Assembly, Washington 2002 and Paragraph 30 added by the WMA General Assembly, Tokyo 2004.

⁷ "Neither sponsors nor researchers can take responsibility for deficiencies resulting from political mistakes and global economic circumstances".

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sanitation measures receive minimal funding at best. Those who hold the reins of power exercise power over technological choice.

In the West, drug companies and their contractors offer large payments to doctors, nurses and other medical staff to encourage them to recruit patients quickly, and do not even have to conduct trials to get paid⁸. There are finder's fees for those who refer their patients to other doctors conducting research. Doctors who recruit the most patients receive additional benefits, such as authorship, even when the true author is a company employee using analysis from the drug company. Those who fail to meet the recruitment goals, query methodology, results, or analysis, are usually dropped from future studies. Thus, in a poor context and where bribes are an essential feature of the culture, the dual role of patient doctor and pharmaceutical investigator can easily promote corruption. There is a fine line between payment for work done and bribery, not always seen by regulatory systems.

In the USA, any company needs US FDA approval -entailing a regime of clinical trials-to be able to market a new machine or technique in the US. However, there appears to be no regulatory mechanism for conducting phase 1 and 2 of its trials in developing countries. There is no collaborating regulatory agency in India for monitoring clinical trials and one company, Surgilight, monitored its own trials in India and South America. India is a prominent recipient in the present climate of outsourcing of skills and talent by developed nations⁹. The Indian government's Health & Family Welfare department brought out new guidelines thereafter on 'good clinical practices for conducting clinical research in India', but very little is written about medical techniques. Guidelines on good clinical practices by the Central Drugs Standard Control Organization under the Ministry of Health, issued recently after cases of gross ethical violations by the Johns Hopkins Institute in collaboration with an Indian medical college went public are still inadequate. Clause 7.3 of the "Clinical Trials with Surgical Procedures/Medical Devices" states that the concept [of regulating medical devices trials] is new and admits that these do not come under the "strict purview" of existing regulatory bodies and vaguely shuffles that responsibility to equally nebulous committees to be set up for such cases.

The Indian Council of Medical Research, which supports new intellectual property development only for research it specifically funds, is currently drafting a proposal for the establishment of an Indian Medical Devices Regulatory Authority. It is hoped that some guidelines and mechanisms of redress will soon come about.

8 For example, in 1996, a study of a migraine drug sponsored by Janssen Pharmaceutica, a unit of Johnson & Johnson, paid doctors \$3,600 for each enrolment. Another study that year sponsored by Organon Inc. on a new birth control pill paid \$1,100 for each patient. And a Wyeth-Ayerst study of drugs for hormone replacement in women paid \$4,581.

9 In 2001, in India there was a controversy on issues of safety, efficacy and ethics when a non-medical scientist at the Baltimore, US-based Johns Hopkins University (JHU) conducted a clinical trial for an anti-cancer drug on Indian patients at the government Medical College Hospital at Thiruvananthapuram, Kerala, without proper authorization from any of JHU's regulatory institutional boards that ought to have considered if it was safe to use the drug on human beings. It also transpired that JHU had no knowledge of the scientist being granted \$2m by a Minnesota-based start-up company called BioCure Medical for conducting the trials.

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In the rich world, "dumping" has become a very dirty word like "slavery" and "colonization." Classical "dumping" does not take place, instead it occurs as double standards in marketing practices. In their country of origin many potentially hazardous drugs may be promoted only for a restricted range of uses, and with certain mandatory warnings. If an importing country has no such requirements, the company can omit the warnings and can promote many more uses¹⁰.

Since the mid-1980s, the Medical Lobby for Appropriate Marketing (MaLAM), based in Australia has carried out an enormous amount of lobbying drug companies about their marketing of certain drugs. Priority is given to misleading advertising in Africa, Asia and Latin America, where the practice is more common, more extreme and more dangerous. While many companies respond, the evidence indicates that misleading marketing practices continue.

The World Health Organization (WHO) started the Essential Drugs Programme (EDP) in 1981 with the aim of strengthening the national capabilities of developing countries in the field of selection and proper use of essential drugs to meet the real needs of people in those countries. The programme also promotes and facilitates local production and quality control, where feasible, of such drugs¹¹. The recent report, The World Medicines Situation, however does not mention the word exploitation, and the only reference to inappropriate use supports the widespread and dangerous nature of the problem¹².

To maintain fragile economies, indebted countries need loans to import basic essential needs such as food, fuel and pharmaceuticals. Loans are available only under conditions of structural adjustment laid out by the World Bank and International Monetary Fund (IMF). The structural adjustment policies usually demanded by these two institutions which have an adverse impact on health and pharmaceuticals include: currency devaluation - so that prices of imported goods such as pharmaceuticals go up; cuts in

10 Hoechst withdrew Baralgan in West Germany potential toxicity. However, Hoescht markets it in several Third World countries. In India it is the ninth top selling brand-name drug. The indications for Organon's Durabolin in the British National Formulary are osteoporosis in post-menopausal women and aplastic anaemia. In Pakistan it is indicated for loss of weight, poor weight gain and malnutrition in children. The drug may produce precocious puberty, in a population which needs food and poverty relief for such indications as malnutrition and poor weight gain.

11 A progress report by the Director-General of WHO to the World Health Assembly in May 1992 reviewed the world drug situation. The progress report, "Implementation of WHO's Revised Drug Strategy: Action Programme on Essential Drugs" stated, among other things, "Approximately half the world's population still lacks regular access to the most needed essential drugs. Moreover, it is estimated that perhaps over 60 percent of the developing world does not have regular access - and socioeconomic deterioration in the developing world over the past decade has made progress difficult. This disturbing estimate for the developing world reflects a drug situation where poorly coordinated policies and strategies, inefficient procurement, uneven distribution, inadequate assurance of quality, unaffordable prices and improper drug utilization are often more the norm than the exception."

"It has become increasingly clear that the current level of cooperation is not sufficient to counter the socioeconomic decline in developing countries. The Director-General emphasizes that Member States will need to increase their efforts significantly to make the most of the present political will and momentum in the development of national drug policies and in the implementation of national essential drugs programmes."

12 The inappropriate use of medicines is not only widespread, it is costly and extremely harmful both to the individual and the population as a whole. Adverse drug events rank among the top 10 causes of death in the USA and are estimated to cost that country between US\$ 30 and US\$ 130 billion each year. The World Medicines Situation WHO 2004.

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government spending - meaning that health subsidies are reduced or taken away altogether; removal of trade and exchange controls - resulting in the limited foreign exchange available being used up by the rich for importing luxury items and the disappearance of low-priced essential generic drugs from the market; and privatization of public sector enterprises, including health care¹³.

In the United Kingdom human medicines are regulated by the Medicines and Healthcare products Regulatory Agency, and in Ireland by the Irish Medicines Board, in accordance with national and EU laws. The EU legislation has recently been changed to ensure that the system continues to protect public health in an enlarged Community and the UK Government are working on implementation. The Seroxat story reveals flaws in the system.

Summary.

The situation regarding the testing of drugs in the Third World, in general, remains unsatisfactory, in that testing can be carried out more cheaply but more importantly without the same safeguards expected in First World countries. Secondly there is no right of continuing to receive the drug once the trial is over.

The arguments over the ethics of drug research are well rehearsed in the literature and we would not want to demonise ethical attempts to advance science and technology. Underlying issues such as poverty and justice are more fundamental issues which underpin the reality of undertaking drug research. If these are not addressed, the arguments related to drug research might seem isolated and difficult to understand.

13 The per capita GNP of the bottom 20 percent of the people in Nepal , for example, is U.S.\$25. If health subsidies are cut and prices of essential food grains go up by even a few cents, these people have to go without health care and food.