NEGLECTED DISEASES, SOCIAL JUSTICE
AND HUMAN RIGHTS: SOME
PRELIMINARY OBSERVATIONS

Paul Hunt

UN Special Rapporteur on the Right to Health

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\[1\] I am very grateful to Judith Bueno de Mesquita, Senior Researcher at the Human Rights Centre, Essex University, for her major contribution towards the preparation of this paper.
I have been asked to speak today on social justice aspects of neglected diseases. Given my background and current work in human rights, I am going to focus on using human rights as a strategy for social justice. My presentation covers three topics. Firstly, I introduce my work as UN Special Rapporteur on the right to health, including on neglected diseases. I then explain in fairly broad terms what I believe to be the ‘value-added’ of human rights to social justice. Finally, I make some preliminary observations about neglected diseases and human rights. Which human rights are affected, and how are they affected, by neglected diseases? And what does human rights law say about responsibilities on States and other actors in relation to neglected diseases?

I. The Special Rapporteur on the Right to Health

In April 2002, the UN Commission on Human Rights adopted a resolution establishing a UN Special Rapporteur on the right to health. Nominated by New Zealand, I was appointed as Special Rapporteur in September 2002.

A Special Rapporteur is an independent expert appointed to monitor, examine and report publicly on either a country human rights situation, or on a major thematic human rights problem. Special Rapporteurs work in cooperation with relevant actors – States, international organisations, donors, NGOs, the private sector and so on - to further the promotion and protection of human rights. This cooperation generally involves attending meetings, visiting countries on official missions, cooperating on projects relating to the right to health and so on. I report annually to the UN Commission on Human Rights and to the UN General Assembly and in these reports I consider, in some detail, different aspects of the right to health.

In my preliminary report to the UN Commission, I set out my main three broad objectives. Each reflects what I see as a key challenge confronting the right to health:

- **First objective**, to promote - and to encourage others to promote - the right to health as a fundamental human right. The right to health is unquestionably part of international human rights law, but still - in my experience - many people do not grasp that it is a fundamental human right. They feel intuitively that the right to a fair trial and freedom of expression are human rights, but they do not instinctively regard the right to health as a human right. In other words, the right to health has not yet gained the same human rights currency as more established rights. So my first objective is to work with others to enhance recognition of the right to health as a fundamental human right.

- **Second objective**, to clarify the contours and content of the right to health. There is a growing national and international jurisprudence on the right to health, but still the legal content of the right is not yet well established. This is unsurprising given the historic neglect of the international right to health. So I would like to clarify the contours and content of the right to health by drawing upon evolving national jurisprudence (over sixty constitutional provisions

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include the right to health or the right to health care); by drawing upon the evolving international jurisprudence on the right to health, such as General Comment 14 of the UN Committee on Economic, Social and Cultural Rights; and also by going back to the basic principles that animate all human rights, such as equality, non-discrimination and the dignity of the individual. My work on neglected diseases relates to this objective. In other words, I want to examine what domestic and international jurisprudence on the right to health says about neglected diseases.

- **Third objective**, to identify good practices for the operationalisation of the right to health at the community, national and international levels. We have to move from fine-sounding norms to effective policies, programmes and projects in relation to various actors including Governments, the courts, national human rights institutions, health professionals, civil society organizations and international organizations. My work on neglected diseases also relates to this objective. Once we have worked out what the right to health says about neglected diseases (objective two), I hope it will be possible to put this into practice.

To make these challenging objectives more manageable, my work focuses on two main themes. **One**, poverty and the right to health. And **two**, discrimination, stigma and the right to health. These themes will enable me to give particular attention to those living in poverty, gender issues, racial and ethnic minorities, indigenous peoples, people living with HIV/AIDS, and other vulnerable groups. Poverty and discrimination/stigma are both, of course, extremely important in relation to neglected diseases.

Beyond these objectives and themes, there are a number of specific issues and interventions which I am addressing, resources permitting, in my capacity as Special Rapporteur.

These issues include the problem of neglected diseases. Since my appointment, I have addressed neglected diseases several times. For example, in July 2003, I undertook a mission to the World Trade Organization, where I discussed, among others, the problem of TRIPS and neglected diseases with members of the WTO Secretariat and Ambassadors and other delegates to the WTO. I also wrote about neglected diseases in my preliminary report to the UN Commission on Human Rights and in my recent report to the UN General Assembly. This month, I am going on an official mission to Mozambique where neglected diseases will be one of the topics I address with the Government, intergovernmental organisations and nongovernmental organisations. I am also currently starting to pursue a human rights analysis of neglected diseases in cooperation with WHO-TDR – I will return to the substance of this analysis shortly. I intend to continue my analysis and advocacy about this issue, which is a great concern from a human rights and a humanitarian perspective.

Following the presentation of my reports to them, both the UN Commission and the UN General Assembly passed human rights resolutions on neglected diseases. The UN Commission resolution specifically: “requests the Special Rapporteur to pursue his analysis of the issues of neglected diseases, including very neglected diseases”. The UN General Assembly resolution: “Recognizes the need for further international cooperation and research to promote the development of new drugs, vaccines and diagnostic tools for diseases causing a heavy burden in developing countries, and stresses the need to support these countries in their efforts in this...”

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regard, taking into account that the failure of market forces to address such diseases has a direct negative impact on the progressive realization in these countries of the right of everyone to the highest attainable standard of physical and mental health”.

II. Value Added of Human Rights to Social Justice

The main focus of my talk today is a human rights analysis of neglected diseases. However, I would like to make some brief observations about what contribution human rights can make to social justice, in other words to creating a fair and equal society. This raises two questions. What are human rights? And what is the valued added of human rights?

What are human rights?

Briefly, human rights can be defined as "that which a person is entitled to have, and do, or to receive from others, and which is enforceable by law." Human rights include a wide range of economic, social, cultural, civil and political rights. They include the rights to health; education; housing; food; a fair trial; freedom of religion; and freedom from torture.

- Human rights have a preoccupation with values and processes at the heart of social justice, such as dignity, equality and non-discrimination, participation and access to justice.

- Human rights are recognised in international law. International human rights law creates a framework of obligation and responsibility for human rights, with the primary obligation falling on States. Yet in recent years there have also been a number of initiatives to develop a clearer understanding of the responsibilities of other actors, including the private sector.

Human rights provide a compelling framework for the formulation of national and international policies for social justice, including in relation to neglected diseases:

- Human rights are underpinned by universally recognised moral values and reinforced by legal obligations. By introducing international legal obligations, the human rights perspective adds legitimacy to social justice as a primary goal of policy-making.

- The norms, values and obligations enshrined in human rights have particular potential to empower marginalized communities and neglected populations. Empowerment can follow from the introduction of the language of human rights into policy, advocacy and law. Once this happens, the rationale is that social justice focuses not on needs, but on rights - on entitlements which have legal obligations on others. In other words, social justice becomes more than a moral obligation, it becomes a legal obligation.

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• Perhaps the most significant value-added of human rights is the framework of accountability it creates for policy makers and other actors whose actions impact on human rights. Human rights primarily create obligations on States. Through ratifying international human rights treaties, States accept obligations - which are binding under international law - to give effect to the recognised rights. States may also, of course, have obligations to give effect to human rights when these are enshrined in domestic law, as they are in a great many countries around the world. International and national obligations require transparent, effective and accessible mechanisms of accountability.

If States fail to do give effect to rights, there are a number of accountability mechanisms which may be available to hold States to account for these failures, such as tribunals, parliamentary processes, Health Ombuds, international human rights treaty monitoring bodies, and so on.

For example, and of particular relevance to neglected diseases, is the growing body of human rights case law at domestic and regional tribunals relating to the failure by States to make accessible drugs for HIV/AIDS and other diseases. Two cases relating to drugs for HIV/AIDS are Cortez v El Salvador which was considered by the Inter-American Commission on Human Rights, and the Treatment Action Campaign v Minister of Health case in South Africa. In the Viceconte Case in Argentina, the Courts ordered the Argentine Government to make available a vaccine against the Argentine Hemorrhaging Fever for three and a half million people. This decision was particularly important since the vaccine is the most effective health measure to combat the disease, which is difficult to diagnose and affects people living in an area with poor access to healthcare.

Such litigation can be an effective way of holding States to account. However, human rights accountability is not limited to litigation before tribunals. There are - and should be more - non-judicial mechanisms of accountability.

• Finally, human rights often provide a useful analytical framework for social justice issues, including neglected diseases. It is this framework to which I now turn. In other words, what does human rights say which is relevant to neglected diseases? And what form of guidance does human rights provide on neglected diseases?

III. A Human Rights Analysis of Neglected Diseases

There are different ways of defining neglected diseases. A recent WHO publication describes them as those diseases that “affect almost exclusively poor and powerless people living in rural parts of low-income countries”.8 It is this definition, which forms the basis of my work on neglected diseases.

As has been extensively documented, neglected diseases result from several problems, including:

• Existing medicines and mechanisms for neglected diseases do not always reach people living in poverty in developing countries. Many of the drugs are too expensive, or are not available in adequate numbers, or are inaccessible geographically, which is a problem particularly in rural areas, because there are inadequate health systems to deliver them.

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The so-called 10/90 gap, which refers to the phenomenon whereby only 10% of global health research is focused on conditions accounting for 90% of the global burden of disease. Diseases, which occur mainly among poor communities living in developing countries, have attracted particularly little research and development (R&D). The market mechanism, which increasingly determines R&D, fails these so-called "neglected diseases" since they do not promise a good return on investment in R&D. At the same time, there is a crucial failure in public policy to adequately address this problem.

As I will explain, both the 'neglected diseases' and the 'neglected communities' dimensions of the problem have human rights implications.

There are, of course, differences between different neglected diseases and this has important implications for human rights. For example, leprosy is now treatable, while buruli ulcer is poorly understood and difficult to treat. HIV/AIDS represents a global emergency - while there are now drugs which help treat the disease and prevent mother-to-child transmission, these drugs are still not accessible to millions of people living with HIV/AIDS in developing countries. In the case of sleeping sickness, there is resistance to existing drugs, which are also highly toxic, and R&D is urgently needed to find new treatment solutions and a vaccine.

The human rights community is becoming increasingly aware of neglected diseases and addressing problems associated with access to drugs. The issue has been raised in the UN Commission on Human Rights, and, in many countries, civil society organisations are starting to use human rights to strengthen campaigns relating to access to medicines.

Today I wish to begin a preliminary analysis on neglected diseases from the point of view of human rights. I should stress that this analysis is highly preliminary and I will welcome your comments today, or informally over the course of this meeting, and after this meeting, when I hope to develop this work. I particularly welcome this opportunity to engage with the group of experts gathered here – experts who come from different sectors, countries and academic backgrounds. This provides a rich opportunity to learn from different perspectives and develop my understanding of the many complexities and nuances in the debate on neglected diseases. It is vital that the human rights analysis takes account of these.

Here I will confine my analysis to two human rights which have a close connection to the issue of neglected diseases, (i) the right to health, and (ii) the right to enjoy the benefits of scientific progress and its applications.

How do neglected diseases impact on these human rights? What entitlements do these human rights include that is relevant to neglected diseases? And what obligations on States and on other actors do these human rights give rise to?

A/ The Right to Health

Under international human rights law it is recognised that everyone has the right to the highest attainable standard of physical and mental health. This fundamental human right is subject to progressive realization: it cannot be realized overnight. There are many norms – both freedoms and entitlements – arising from the right to health. Here I focus on one set of entitlements which is an integral element of the right to health and which has particular importance in relation to
neglected diseases. For a further discussion of the sources and scope of the right, see my preliminary report to the UN Commission on Human Rights.  

This set of entitlements is to make available and accessible quality health care services, facilities and goods, and this includes essential medicines. Many of the existing drugs for neglected diseases are essential medicines as defined by WHO.

This set of entitlements means that essential medicines must be available, accessible and of good quality. If essential medicines must be available, accessible and of good quality - what might this mean in relation to neglected diseases?

**Availability** means that essential drugs must be made available in adequate numbers within countries where there is a need for them. Of course, a significant problem relating to drugs for neglected diseases is that many drugs are not available. In other words, they do not exist in sufficient numbers within particular countries.

**Accessibility** means that they should be made accessible geographically, economically and on the basis of non-discrimination to the people who need them. In recent years, the UN Commission on Human Rights has emphasised the particular importance of access to medication – it has adopted resolutions stating that “access to medication in the context of pandemics such as HIV/AIDS, malaria and tuberculosis is one fundamental element for achieving progressively” the right to health. Yet without targeted interventions by governments, international organisations of pharmaceuticals, drugs for neglected diseases are not always economically accessible and they are also not always geographically accessible for communities who need them.

**Quality** means that the drugs have to be scientifically and medically approved and of good quality. I would add to this that the drugs administered should be effective in relation to any particular strain of a disease which is prevalent in a given setting.

What do these availability and accessibility and quality aspects look like in practice? Perhaps I can best illustrate this with some examples.

- WHO's new “3 by 5” campaign is a promising move from the point of view of the right to health on account of its aim to provide three million people in developing countries, and countries in transition, with anti-retroviral therapy. In other words, it is aiming to make these drugs available and accessible.
- The Argentine case I referred to previously involved a decision ordering the government to manufacture vaccines for 3.5 million people at risk of Argentine Hemmaeorgic fever. This represented an important victory to make the vaccine available.
- In Brazil, the decision of the government to provide anti-retrovirals free of charge to all who need them helped make these drugs economically accessible.

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10 For completeness I note that the analytical framework mentioned here includes a fourth component-acceptability-which I have omitted in these remarks in the interest of brevity. Acceptability is identified in CESCR's General Comment 14.
11 For example, see E/CN.4/2003/L.33, 11 April 2003, para 1.
The decision of pharmaceutical companies to lower significantly the prices of drugs, or provide them free of charge, as Novartis (to give just one example) has committed to do to combat leprosy, can also be seen to contribute to the realization of the right to health. Novartis has ensured that drugs for leprosy are economically accessible to those who would not otherwise be able to afford them and this has had a significant impact on combating the disease.

These cases all refer to making existing drugs available and accessible.

But how does the availability and accessibility analytical framework relate to diseases for which there are no drugs? R&D is an essential component of making drugs available in the first place. In other words, in relation to some diseases where there is no vaccine, such as AIDS or malaria, or no treatment, such as drug-resistant strains of tuberculosis, there is a responsibility on States, and other actors, to do all they can to make drugs available in the first place, through R&D.

A further dimension of this right to health framework, in addition to availability and accessibility of drugs, is the quality of the drugs on offer. The drugs available to people living in poverty in developing countries are not always of adequate quality. This is dramatically illustrated by the problems surrounding access to drugs for malaria in Africa. Up to 80% of malaria in Africa is resistant to chloroquine, the cheapest standard drug against the disease. Other effective drugs – such as malarone or doxycycline - are too expensive for most people in African countries with high incidence of malaria. In the case of sleeping sickness, there are drugs available which can cure the disease, but which are, as I understand it, toxic and ineffective. The right to health entitles people to good quality drugs – in other words, States and others must find a way to ensure that quality drugs are available. This may involve initiatives to make existing quality drugs available, or where there are none, R&D must be conducted to make these drugs available.

I will return to talking about the nature of responsibilities, and the duty-bearers of these responsibilities, shortly. I wanted to quickly sum up my comments about neglected diseases from the point of view of the right to health. Essentially, people are denied the enjoyment of their right to health:

- (1) where there has been inadequate R&D into developing appropriate and effective drugs. A human rights approach focuses on addressing the needs of the most disadvantaged communities –neglected populations- and yet the 10/90 gap clearly illustrates this is not occurring in practice.

- (2) where there are appropriate and effective drugs, but they are often not economically accessible for poor people living in developing countries; intellectual property regimes have meant that many people have not had access to cheaper generic versions, and even where cheaper generic versions are available, these may still be too expensive.

- (3) where there are affordable and appropriate drugs, they often fail to reach neglected communities who need them because of inadequate health infrastructures to deliver them.
B/ The Right to Enjoy the Benefit of Scientific Progress and its Applications

The right to health is closely linked to the realization of the right to enjoy the benefit of scientific progress and its applications.\textsuperscript{12} Over the past decades, many important developments in molecular biology and biotechnology have created or improved techniques to prevent, treat or cure a wide variety of diseases.\textsuperscript{13} However, these developments have been biased towards conditions which are prevalent in developed states, and not towards neglected diseases which primarily affect people living in poverty in developing countries. This is effectively denying neglected populations their right to enjoy the benefits of scientific progress.

However, there are some recent initiatives which give hope for the fulfilment of this right. For example, the Drugs for Neglected Disease Initiative (DNDi) is a particularly welcome development from the point of view of human rights, since its basic objective is to develop and apply scientific progress to those diseases which hinder the realization of the right to health for many people around the world.

C/ Obligations

As I mentioned earlier, part of the value-added of human rights is, firstly, their recognition in international law, and, secondly, that States and other actors have obligations towards making these rights a reality. International law establishes a framework of obligations on States and other actors.

(i) What are the Obligations on States?

When States ratify international human rights treaties, they have an obligation to give effect to its provisions. \textsuperscript{147} States around the world have ratified the International Covenant on Economic, Social and Cultural Rights.

In relation to the right to health, this treaty imposes an obligation on States to take steps necessary for:

"the prevention, treatment and control of epidemic, endemic, occupational and other diseases"(Article 12)

To give effect to the right to enjoy the benefits of scientific progress, States which have ratified ICESCR have an obligation to:

"take steps necessary for the development and diffusion of science." (Article 15)

If we read these provisions together, States may be considered to have an obligation to take steps necessary for the development and diffusion of science for the prevention, treatment and control of diseases.

The importance of the obligation to make essential drugs available has been recognised by the UN Committee on Economic, Social and Cultural Rights, a body composed of independent experts which is responsible for monitoring ICESCR. This Committee has stated that this obligation is a “core obligation” on States. In other words, if a State is not making essential drugs available, it is failing to fulfil its international legal obligations towards the right to health.

\textsuperscript{12} International Covenant on Economic, Social and Cultural Rights, art 15.1(b)

\textsuperscript{13} Médecins Sans Frontières, Access to Essential Medicines Campaign, \textit{Fatal Imbalance}, 2001, p. 16.
While the opinion of the Committee is not legally binding, it has been influential in shaping opinion of States, regional and domestic courts, and civil society. In other words, the Committee’s opinion is widely considered to have significant legal weight.

So what is the exact nature of these obligations on States? How are States supposed to give effect to these obligations to make quality drugs available and accessible?

I do not have time to elaborate extensively on the nature of obligations on States. But I would like to make several brief points in relation to the following questions (i) What types of actions must States take to be considered in compliance with obligations under ICESCR? (ii) How should we interpret the obligation ‘to take steps’ which I just mentioned? (iii) Do States just have obligations at the domestic level or do they also have an international responsibility towards the promotion and protection of these rights in other countries?

(ii) Types of Actions

States are considered to have three types of responsibilities towards human rights under international human rights law: obligations to respect, protect, and fulfil.

• The obligation to respect means that States must, among other things, refrain from actions which deny people their right to health. There are several examples of obligations to respect which apply to neglected diseases. One of these relates to an obligation on States to ensure that their policies, and actions within the framework of international institutions, are respectful of the right to health in other countries. I will return to this obligation when I talk about the international dimension of States obligations.

• The obligation to protect means that States should, for example, ensure that privatization of the health sector does not constitute a threat to the availability, accessibility and quality of health care goods, services and facilities. This obligation has a relevance to neglected diseases since increasing reliance by States on the private sector to conduct R&D has meant that the market, to a large degree, determines R&D.

• The obligation to fulfil includes an obligation to promote medical research. It also includes an obligation to take positive measure that enable individuals and communities to enjoy their right to health. Clearly in the case of neglected diseases, positive measures are required.

(iii) The Obligation to Take Steps

The right to health includes a range of entitlements. It is clear that many of these entitlements are difficult to provide immediately; it will take time to develop and implement strategies to meet entitlements. Finding new ways of preventing or treating neglected diseases, finding solutions to lowering the costs of drugs, and building up health systems to deliver these drugs where they are needed – all these interventions will take time. However, States must show that they are taking steps towards providing essential medicines or promoting R&D into new drugs in a deliberate, concrete and targeted way.14

(iv) Domestic and International Obligations

International human rights law imposes obligations on States to give effect to human rights within their jurisdictions. With regard to neglected diseases, the governments of developing countries must take targeted steps towards ensuring that effective drugs are made available and accessible to the populations that need them.

However, international human rights law also recognises that States have international responsibility towards the right to health. These arise from human rights provisions of international assistance and cooperation. Thus, states should take actions that promote and protect the right to health in other countries, and they should refrain from taking actions that jeopardise the right to health in other countries. This may involve a responsibility on rich countries to promote R&D into neglected diseases even though these diseases do not have a high incidence, or occur at all, within rich countries. It also involves an obligation to promote international policies, either bilaterally or within the framework of inter-governmental institutions, that are conducive to addressing the problem of neglected diseases.

Let me give an example to illustrate what I mean by these international obligations in relation to the right to health. On 30 August 2003, the WTO decided that countries producing generic copies of patented drugs under compulsory licence could now export drugs to countries with no or little drug manufacturing capacity – this was an important decision and consistent with the human rights concept of international assistance and cooperation. Moreover, last month, the Canadian Government introduced a Bill into the Canadian Parliament to amend the Patent Act and Food and Drugs Act in a way which would make it easier for Canadian companies to produce, and developing countries to import, generic lower cost drugs. The Canadian patent law is not currently restricted to a narrow range of diseases. The Canadian initiative is an important example of how developed countries can help to improve access to medicines to fight diseases in poor countries: it reflects Canadian human rights responsibilities of international assistance and cooperation.

(v) The Role of Non-State Actors: NGOs and the Private Sector

International human rights law imposes obligations on States. In general, it does not impose obligations on non-State actors. However, it is increasingly responding to the increasing role played by non-state actors in the economic and social spheres, for example by providing guidance on the types of responsibilities that non-state actors have. While ultimate responsibilities lies with states, a resolution recently adopted by the UN Sub-Commission on the Promotion and Protection of Human Rights states that even though States have the primary responsibility towards human rights, “transnational corporations and other business enterprises, as organs of society, are also responsible for promoting and securing the human rights set forth in the Universal Declaration of Human Rights.” The Universal Declaration on Human Rights recognises that everyone has the right to a standard of living adequate for the health and well-being, including medical care. This resolution also emphasises that TNCs and other business enterprises shall respect and contribute towards the realization of the right to health and refrain from actions which obstruct or impede the realization of this right. The relationship between the right to health and the private sector raises important issues but need further careful attention.

(vi) Conclusions on Obligations

As I have noted, international human rights law recognises that the primary obligation lies with States to develop solutions to the problem of neglected diseases. Due to the fact that the right to health gives rise to domestic and international obligations, all States should be considered to have a responsibility under international law to take action to address neglected diseases, in other words, to redress the failure of the market and public policy that is currently hampering the fight against neglected diseases.

This is not to imply that pharmaceuticals are free of responsibilities in relation to the international right to health. There is increasingly recognition of the crucial role and responsibilities of the private sector in the promotion and protection of the right to health. There are examples of domestic legal systems where legislation has been used to address the policies of pharmaceutical companies. Recently, the Competition Commission in South Africa found GlaxoSmithKline in breach of the South African Competition Act for excessive pricing of its antiretrovirals.16 On the other hand, pharmaceuticals have taken action conducive to enjoyment of the right to health. On the same day as this finding by the Competition Commission, GlaxoSmithKline reduced the not-for-profit price of Combivir – the backbone of HIV/AIDS treatment regimens currently recommended by the World Health Organisation (WHO) – from US$ 0.90 cents to 0.65 cents per day.17

IV. Concluding remarks

In my preliminary report to the UN Commission on Human rights and in my recent interim report to the UN General Assembly, I have characterized neglected diseases as a major human rights issue. In this paper, I have begun the process of explaining some of the human rights dimensions of neglected diseases and the 10/90 gap.

Some human rights dimensions of neglected diseases arise from the general features of human rights, such as its preoccupation with disadvantaged individuals and neglected populations, as well as its emphasis on informed participation and transparent mechanisms of accountability. Other human rights dimensions of neglected diseases arise specifically from the right to health, such as the availability and accessibility of quality essential drugs.

In this paper, I have done no more than signal some of these human rights and right to health dimensions. All require much closer attention. In the meantime, your comments and suggestions will be most welcome.

Professor Paul Hunt
Department of Law
Human Rights Centre
University of Essex
Colchester
England

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paulhunt28@hotmail.com and jrbuen@essex.ac.uk

16 Media Release from the Competition Commission, 16 October 2003