Right to health through litigation?
Can court enforced health rights improve health policy and priority-setting in poor countries?

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"Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services". (Article 25.1 of the Universal Declaration of Human Rights, 1948)

"[States parties] recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health". (International Covenant on Economic, Social and Cultural Rights of 1966)

The aim and relevance of the project
This multidisciplinary project aims to systematically investigate whether litigation can make health policies and -systems in poor countries more equitable by forcing policy-makers and administrators to take seriously their human rights obligations.

A majority of the world’s governments are obliged through international treaties or national constitutions, or both, to respect, protect, promote and fulfill the human right to health. In most cases, this has not been an enforceable legal right. However, cases regarding the right to health care are increasingly brought before the courts. In a number of low-and middle-income countries – first in Latin America, later in Africa and Asia, court decisions have granted access to certain forms of medical treatment. These are decisions with potentially great implications for how health sector resources are prioritized and allocated, but so far there is little systematic knowledge of the actual effect of such cases on health policy formation, implementation and spending. Do they have a significant effect in practice? And, if so, do they contribute to more – or less – justice in health service delivery?

The project aims to contribute to filling this gap. To know more about consequences of health rights litigation under different circumstances is important from the perspective of health sector reform. Both because of its constructive potential – the possibility of developing and facilitating health litigation as an instrument for health policy reform – but also for ‘defensive purposes’. Health litigation already takes place, and increasingly so, in poor countries. It has implications for policy and spending. This may be positive from the perspective of justice in health care, but it could also represent a threat to systematic priority setting and equity, and raises difficult ethical issues.

The international donor community has shown a growing interest in social rights litigation and has been willing to fund health rights litigation. This adds to the importance and urgency of gaining more knowledge concerning the effects of the legal cases are in terms of health policy and health service delivery. To do so requires a radically multidisciplinary approach, taking account of the full range of aspects involved: medical, economic, legal, ethical, social and political. The project aims to achieve this by teaming up experts in the relevant fields, who shares a commitment to provide sound knowledge that can improve equity in health care.

The proposed project will address four sets of questions:

- How does litigation on health rights affect health policy and spending in low- and middle-income countries?
- Does it lead to more or less fairness in treatment of various groups of patients?
- How do courts negotiate this technically and ethically complex and often politically sensitive terrain? Do international human rights norms enter into domestic litigation in these cases?
- What drives the “litigation wave”? And what determines whether health rights litigation succeeds in shaping health policy?

**Background, knowledge status, research questions and approaches**

The research questions indicated above outline a relatively ambitious research agenda, extending beyond the current application. The following outline specifies how we will approach them within the resource frame of the current project proposal.

(1) *How does health rights litigation affect health budgets, health policy formation and – implementation?* The question of what the consequences of health rights litigation are, in terms of health spending and policy and actual health service delivery, calls for a multi-pronged approach. We need to see whether there are noticeable shifts in health spending in countries where there have been significant health rights judgments. And, if interventions backed by litigation receive more in practice, we need to find out where the money come from – is it taken from other patient groups, from other parts of the national budget, or from outside donor sources? This requires in depth investigations of how the litigation is given effect; what happens with regard to spending on the relevant forms of medical treatment, and to the overall health budget? Since there are many reasons for changes in health spending and for allocations to particular types of treatment, budgetary data must be supplemented by interviews with key actors. Cost-effectiveness analyses are also relevant to consider the gains from providing the relevant forms of treatment. Furthermore, it is necessary to examine the policy process and documents to see to what extent, and how, judgments are reflected in health policy and legislation. Litigation, or threats to litigate, may also play a role in the implementation process and affect the delivery of the health services.

In addition to assessing what has in fact been happening in the (mostly middle-income Latin American) countries where there has been successful health

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right litigation, we want to see, through economic modeling, what it would mean to have such judgments in other (low-income African and Asian) countries, with different resource constraint and institutional structures.

(2) Does health rights litigation lead to more or less fairness in treatment of various groups of patients? To investigate the effects of litigation on priority setting and social justice, we need to know who benefits, both in terms of diagnosis and social background. A starting point here is to look at the forms of treatment that are the subject of successful litigation. However, in order to assess distributional consequences of such judicial decisions, medical evidence is needed regarding the burden of disease and effectiveness of treatment for the condition in question. This requires medical expertise combined with bio-ethical analysis.

We know that a large part of the cases, particularly the early ones, concern people living with HIV/AIDS, but there are also other cases, regarding interventions ranging from essential medicines to high-cost treatment for cancer, multiple sclerosis, and kidney failure. Whether successful litigation and a higher priority to these treatments, makes the health system more just, depends on what the prior situation was for the patient groups relative to others. (Were they previously marginalized, or is litigation primarily assisting those who already are in a stronger position?) To assess effects on social justice it is also relevant to look at who brings these cases, and what the court orders are – particularly whether decisions only affect the individual case or all similar instances. To evaluate the fairness of the outcome, the factual situation with regard to the effects of litigation on the distribution of health resources, should also be analyzed from the perspective on ethical theory on priority setting in health care.

(3) How do courts negotiate this technically complex and often politically sensitive terrain? And how do international human rights norms enter into domestic litigation in these cases? Health policy is traditionally the domain of politicians and judges venturing into this terrain being accused of meddling in politics. This makes it particularly interesting to look at the nature of the judgments that are forthcoming in these cases – and to examine how they engage political actors and policy-processes. Do the courts grant individual relief in these cases? Do they dictate government policy in specific fields? Are there cases where they engage in a dialogue with policymakers? By studying the judgments and the litigation processes, we also want to

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assess the use and importance of international human rights norms and regional human rights jurisprudence (in particular from the Inter-American Court of Human Rights) on the right to health, in domestic health right litigation. Are they relied on directly or do they work only though domestic law?

(4) What drives the increase in litigation on health rights? And what does it take for such litigation to be successful? There is some literature describing health right litigation in various Latin American, African and Asian countries, but no systematic attempt to understand what has lead to the emergence and spread of health right litigation globally, or what it takes for such litigation to succeed. There appears to be a wave of litigation starting with cases in a handful of Latin American countries, and spreading from there to the rest of the continent, and to other regions. Is it coincidental that similar cases arise in various parts of the world at the approximately same time? Is the spread a matter of ad hoc diffusion or learning between groups litigating in different countries? Or is what we see a result of more organized efforts? By investigating selected litigation processes we may gain a better understanding of what drives the process – including to what extent efforts by transnational networks of NGOs and activists, academics and donors contribute to the development. It also allows us to explore the importance of cross-national learning in these cases.

In addition to understanding what drives this expansion in health right litigation, we are interested in the conditions under which such litigation is successful, both in terms of winning in court, and more broadly, in the sense of shaping health policy (the two are not necessarily linked). Besides the effects of judgments, the litigation process itself may affect health policy debates and outcomes, directly and indirectly. It may set the agenda, cast the debate in terms of rights, and sway public opinion – or it may have few notable effects. By following selected litigation processes, we may gain more insights into the circumstances under which health right litigation succeeds and influences policy processes. In this context we want to explore how health policy effects of litigation are affected by various institutional set-ups. Research on courts and marginalized groups show that access to the legal system and support structures varies hugely and is a major factor in explaining who benefits from court cases. Low entry thresholds and public litigation assistance characterize several

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7 We know that case material from other countries are used in several health rights such cases, we also know that for example legal scholars from American universities have played a role in health litigation abroad, but we lack a more systematic understanding of these influences.

countries where health right litigation proliferates, but there is considerable variation in such ‘auxiliary institutions’. In some cases, such as in Brazil, they have, in addition to litigation, a direct, quasi-judicial role in law reform and policy formation (including through participatory processes), and this is particularly interesting to explore.

**Methods and Case Selection**

Given the multidisciplinary nature of the study, it will necessarily involve a range of different methods of data collection and analysis, from medical and epidemiological analysis of morbidity patterns and treatment options and effects, and ethical analysis on fairness in health care; via economic analysis of budgets, resource flows, cost-effectiveness of interventions and economic modeling; socio-legal analysis of litigation processes and policy processes; to legal analysis of judgments. Throughout the analysis, documents and secondary material will be combined with interviews of policymakers, activists, judges, lawyers and bureaucrats.

In terms of cases, the final selection will depend on the outcome of the initial state of the art study, but in general terms, we want to start with Latin-American cases with the most experience from health right litigation, both in terms of time and volume. We also want to include cases with a variety in institutional set-up, socio-economic conditions and legal traditions. Colombia, Costa Rica, Peru, Argentina and Brazil are interesting cases in this regard, and the team has been assembled with a view to include in-depth insight in these country cases. Beyond Latin-America, we want to include African and Asian cases where health litigation has taken place, or is in the pipeline. This includes South Africa, as the African county with most relevant cases, and possibly Nigeria and Uganda, and from South-East Asia, India, with several interesting health rights cases, as well as Bangladesh, where such litigation is now being developed.

**The research team**

The research milieus behind this proposal, and the multidisciplinary team of participating researchers, are well placed to undertake the study and contribute to important new knowledge in this field.

Health rights litigation represents important and complex challenges politically and academically. The right to health, in particular in the context of HIV/AIDS is an area of growing concern internationally, and health right litigation concerns a central social rights issue where current strategies are challenging existing policies. Health rights cases involve issues of medical knowledge and technology, ethical and legal issues and have potentially huge economic consequences. Most existing studies looking at this complex do, however, stay within one academic discipline, and are usually geographically limited to one region. This project spans the natural sciences, social sciences, law and humanities and brings together a rich array of academic perspectives; medicine, medical ethics, human rights, law, politics, sociology, economics – and an equally multidisciplinary team of researchers, who also hold deep knowledge on a range of empirical contexts. Each of these academic fields has much to contribute to the understanding of the phenomenon of health rights litigation and its policy consequences, but it is particularly when they are combined that the full potential can be released. The multi-disciplinary and multi-regional nature of the proposed research project – and the team – Is thus a major value, and represents a genuinely novel approach. At the same time the project draws on the participating researchers’ long term research efforts, and wider research conducted
within the institutions. Gender dimensions are central in health policy, and the gender balance of the team (six women, including team leader, five men) is thus important.

**Norwegian Research Partners**

*The Chr. Michelsen Institute* is Norway’s largest development research institute. CMI has a long-standing tradition for research into areas relevant for this study. Three research programmes are of particular relevance:

- **The Courts in Transition** programme, headed by Siri Gloppen, has a long standing focus on the relationships between litigation and policy; on social rights litigation; and on courts and marginalized groups. This feeds directly into the proposed project. The programme also has considerable experience in building interdisciplinary, inter-regional networks around socio-legal research, and in particular facilitating south-south exchanges.

- **The Global Health and Development** programme headed by Ottar Mestad, has as its focus areas a) the formation and implementation of national health policies, and b) priority setting in the health sector. The knowledge on health economics, health systems and priority setting which has been developed as part of this research programme will be important building blocks for this new research, while the new programme will produce knowledge that is important in order to understand aspects of the health policy formation process.

- **The Chr. Michelsen’s Human Rights Programme** has a long tradition of research into social and economic rights, and the project is in line with the current priority on investigating relationships between international human rights norms and national and local level norms and practices.

**The Division for Medical Ethics**, Department of Public Health, University of Bergen has, in collaboration with the Centre for International Health established a cross disciplinary research group concerned with the ethics of priority setting in global health. The group works on the development of procedures, principles and criteria for evaluating priority setting in health, measuring equity in health, economic evaluations of health interventions, case studies on priority setting, and how to involve laypersons in priority setting. Professor Norheim, who heads the division, is supported by a young investigators award (YFF) for the project “The ethics of priority setting in global health” which explores how efficiency can be incorporated with fairness.

**International Research Partners**

*Harvard Law School Human Rights Program* (HRP) seeks to give impetus and direction to international human rights work at Harvard Law School, both in terms of research and education. In its twenty-third year, the HRP fosters course work and participation of students in human rights activities through fellowships and clinical work, and plans and directs international conferences and roundtables on the leading human rights issues and debates in the field.

*Centre for Applied Legal Studies* (CALS) is the oldest public interest law organisation in South Africa and its position at Wits University means that it is uniquely placed to combine rigorous scholarly research with high quality advocacy and litigation. Health right litigation has been central to the centre, which for 14 years has been home to the AIDS Law Project (which became independent in 2006, but

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9 According to the 2006 Review of the CMI (commissioned by the Research Council, RCN, and lead by Göran Hyden) CMI is the leading development research institute in Norway and, in the European context, it “plays in Champions League”.

10 The “Courts in Transition” programme was rated “excellent” in the 2006 review (ibid).
continues cooperation). CALS also have long-standing experience in other areas of socio-economic rights (housing, water and education), gender based violence, customary law and equality.

*Ain o Salish Kendra* (ASK), is a legal aid and human rights resource centre combining litigation, advocacy and research. It provides free legal aid to the poor and has a special consultative status with UNECOSOC. ASK seeks to create awareness of legal and human rights so as to empower citizens to negotiate their rights. It is committed to campaigning for reform of discriminatory and repressive laws to eliminate systemic social, legal and political discrimination. Recently ASK has also entered the field of health right litigation, which is novel to Bangladesh.

### The team

**Norway:**

*Siri Gloppen* – team leader – (CMI and University of Bergen, Dept. of Comparative Politics) political scientist with wide experience from court and litigation research in Southern and East Africa

*Roberto Gargarella* – (CMI and deTella University, Buenos Aires) Professor of law. Has published widely on social rights and social rights litigation and jurisprudence, particular focus on Latin America.

*Ottar Mæstad* (CMI – economist, specialising in health economics in developing countries)

*Ole F Norheim* – Professor of medical ethics (University of Bergen) and physician (Haukeland Hospital). Wide academic and practical experience from priority setting in health in developing as well as developed countries

*Bruce Wilson* (CMI and University of Central Florida) political scientist with broad knowledge on legal politics in Latin America generally and Costa Rica in particular

**International partners:**

*Alicia Yamin* (Harvard Law School, Human Rights Programme and School of Public Health) Extensive work on health rights in Latin America, including litigation experience.

*Mindy Roseman* (Harvard Law School, Human Rights Programme, Academic director) broad insights in human rights, the right to health and public interest litigation.

*Raquel Dodge* (Ministério Público, Brazil and Harvard Law School) Combines academic work with long experience as federal prosecutor in Brazil. She has been Deputy Federal Prosecutor for Citizens Rights (the Brazilian version of ombudsman) and co-founded the National Association of the Public Ministry on the Right to Health. Actively involved in health right litigation as well as quasi-judicial work on health reform.

*Carole Cooper* (Centre for Applied Legal Studies) lawyer with broad academic and practical experience from health litigation and policy making in South Africa

*Faustina Pereira* (Director, Ain o Salish Kendra) Researcher, activist and Supreme Court advocate engaged in human rights litigation in Bangladesh.

*Mark Goodale* (George Mason University). Professor of Conflict Analysis and Anthropology. Expert on transnational human rights networks, the relationship between culture and human rights, the role of courts within broader social and political processes, and the relationship between transnational, domestic, and local norms.

A doctoral candidate will be recruited. Applications will be invited from all fields, but looking in particular for good candidates with a background in medicine.11

The project will also involve **graduate students** from participating institutions.

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11 Within all the relevant fields there are team members experienced in PhD supervision, and the participating institutions, in Norway and internationally, continuously hosts doctoral candidates and have support structures for doing so that have proven successful in the past.
Project Plan
2008:

- **State of the art study.** Comprehensive desk study aiming to: (a) provide an up to date map with regard to relevant health right litigation globally; (b) provide a state of the art with regard to research in the field (including research on social rights litigation, the right to health and health law; health economics; priority-setting and medical ethics; health policy and development aid). This will be converted into an internationally publishable review article. (Jan – March 08)

- **A Concept Paper,** drawing on the state of the art study will be developed to provide a joint theoretical and methodological baseline for the project. (March-May 08)

- **Inception workshop,** Bergen May 2008

- **Pilot studies** (mid 08 – mid 09):

  **Pilot I: “Effects of health right litigation on health spending”** (Main responsibility: Mæstad and Wilson). This study will be the first leg of the aim to analyse the actual effects of litigation on health policy. Two sets of questions will be addressed. First, to what extent litigation has lead to a change in the spending patterns of the health sector. Have more resources been allocated to the litigation interventions? And has this happened at the expense of other parts of the health sector? This question will analysed through reviews of policy documents and budget allocations. Second, we are interested in the cost implications of the (perhaps) more hypothetical case that health policies are completely reformed following the outcomes of litigation processes. This analysis will be based on data on disease patterns in the country, together data on the costs of intervention. Final selection of pilot case will be based on the results of the desk study, but Costa Rica is seen to be a good first case. (It has had an extensive volume of health litigation over some time, starting with AIDS, moving to other treatment; the judgments have been implemented; the country is small, stable, and has reliable statistics, providing reasonably good conditions for tracking expenditure and effects.  

  **Pilot II: “Dialogic judgement? Nature of engagement between courts and policy-makers?”** (Main responsibility: Gargarella). This pilot study will be the first part of a comparative investigation into the nature of health judgments and the different ways in which courts relate to policy makers and impact on policy formation. This fist study will investigate court orders made in health cases in three Latin-American countries, including an in-depth study of litigation and quacy-judicial structures for health right litigation and policy reform in Brazil.

  **Pilot III: “Role of international human rights norms, NGOs and donors in health right litigation”** (Main responsibility: Gloppen) This pilot tracks the international interactions and influences in five important health litigation cases. The cases, spanning Latin America, Africa and South East Asia, will be selected on the basis of the desk study.

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2009;

- **Complete pilots** and write articles for international journals based on each pilot study.
- **International workshop** (mid 2009) to deliberate on the preliminary findings and bring together partners and international experts to prepare for the second stage.
- **Stakeholder seminars** in countries of study to disseminate preliminary findings and receive correction and input, write and distribute policy briefs.
- **Post-graduate courses**, in Bergen and with cooperating institutions
- **Main phase studies**: (mid 2009 – end 2010)

I: **“Effects of health right litigation on health spending”**. Based on conclusions and insights from the pilot, the study will expand the analysis of the effects of litigation on health policy to a broader range of countries. The set of questions analysed will be the same as in the pilot. Modeling based on economic as well as epidemiological parameters will be used to estimate effects of similar litigation in other economies (poor, African and Asian countries).

II: **“Dialogic judgment? Nature of engagement between courts and policy-makers?”** Expanding on the pilot study, this study will continue the comparative investigation into the nature of health judgments and how courts relate to policy makers. It will expand the scope geographically; in terms of more in-depth analysis of the various ways court judgments may impact on policy formation, as well as studies of what it is that determines the form of the judgment and the legal-political interactions.

III: **“Role of international human rights norms, NGOs and donors in health right litigation”**. This study expands on the conclusions in the pilot and will analyzing more cases based on trends in the material, including ‘failed’ cases. The study will consider whether cases that do not succeed in getting a judgment supporting the litigant’s claim for a right to health, may still have policy effects. It will also pay more attention to what makes various litigants succeed (or not) in health litigation cases.

2010:

- **Complete main phase study** and write articles for international journals based on each pilot study.
- **International workshop and conference** to bring research partners deliberate on the findings and enhance the analysis.
- **Policy briefs and stakeholder seminars** in countries of study to disseminate findings to local activists, policy-makers and educators.

**Dissemination plan and communication with users**

The project puts a premium on academic stringency, but is also driven by a strong commitment to advance health rights of poor people through improving health policy and implementation. Communication with various groups of users (policy-makers, activists, judges, lawyers, donors) are crucial to ensure both the validity and relevance of our research and the dissemination of our findings. The various partners to the project all have long standing experience enabling communication and dissemination though publications, meetings and training. This will include, among other:

- 6-8 CMI Policy Briefs, making findings accessible to a wider audience
- Stakeholder meetings, training for various groups of users and students
**Academic outputs:**

**2008:** One internationally published review article, one theoretical article

1. **“Right to health through litigation?”** Review of health rights litigation in poor and middle income countries in Latin America, Sub Saharan Africa and Asia, and the literature on the political and economic implications of health rights litigation.

2. **“Making sense of health right litigation”** Concept paper refining the theoretical framework and developing the interdisciplinary methodology for the study.

**2009:** At least seven internationally published articles;
Seven free-standing, but related, internationally published articles, preferably a special issue of a peer-reviewed journal:


4. **“Health rights litigation in South Africa and Brazil: how it has shaped health policy formation and implementation”** (Based on the pilot studies on health policy- and budget analysis)

5. **“Do rights bring justice to health care?”** Reflections on the distributional outcomes of health litigation in the cases of Costa Rica, Brazil and South Africa, from the perspective of the ethics of priority setting in health.  
   "“Dictate or dialogue? Court-policy relations in health rights jurisprudence”

6. A comparative study of how judges engage processes of health policy formation and implementation in three Latin American cases.

7. **“The role of international human rights norms in domestic health rights litigation.”** A systematic survey of health rights litigation in six countries, from three continents: Latin America; Africa; and Asia.

8. **“What drives the international ‘wave’ of health rights litigation?”** An analysis of five landmark health rights cases, mapping international interactions, resource streams and jurisprudential influences. (Based on the sub-study on litigation dynamics.)

9. **“When does health rights litigation succeed?”** An analysis of what distinguishes litigation processes where health right litigation is successful in terms of winning in court based on five successful landmark cases, and two unsuccessful cases.

**2010:** Four internationally published articles placed in high-impact journals.

10. **“Health rights litigation: implications for health spending, policy formation and implementation in poor countries”** A comparative study of policy and budget implications of health litigation in middle-income countries in Latin-America and Africa. Uses economic modeling to analyse implications of a similar development in the poorest countries. (Based on the sub-study on health policy- and budget analysis)

11. **“Do rights bring justice to health care in poor countries?”** An evaluation of the distributional outcomes of health right litigation with respect to essential drugs in poor countries. (Based on the pilot study on access and equity analysis)

12. **“Dialogic justice - new developments in health rights jurisprudence in the South”** A comparative study of how judges engage processes of health policy formation and implementation in Latin America, Africa and Asia, with emphasis on dialogic forms of justice delivery, and on the role of international human rights norms in domestic health rights litigation. (Based on the pilot study on health jurisprudence analysis).

13. **“When does health rights litigation succeed in shaping health policy and implementation: Latin American, African and Asian cases compared ”** An analysis of what distinguishes health right litigation which is successful – not only in terms of winning in court, but in terms of actually influencing policy processes, litigation and implementation of health care delivery. Focus is not only on the judgment, but also on the litigation process, taking account of domestic as well as international factors and resources. (Based on the pilot study on litigation dynamics.)