Introduction – Consumer medicine

Aaro Tupasela
Department of Sociology
University of Helsinki, Finland

The chapters in this book all address an important area relating to the delivery of medical services, namely the development of consumer medicine. The chapters have come about from presentations that have taken place in two separate meetings; one on genetic self-testing, and the other on 'medical tourism' or cross-border medical treatment. These topics, although somewhat different, can be grouped under the rubric of consumer medicine in that increasingly the relationship between the patient and various products and services is mediated through market mechanisms relating to consumption and advertisement, as opposed to the physician alone. This shift in power relations and roles between actors has brought about not only new opportunities for companies seeking to market and sell their new products, but also ethical challenges in the way these activities and some of their consequences can, and should, be governed and regulated. This is not an easy task since the markets for many medical products and services have become transnational, challenging the traditional notion that governments operate in relation to geographical boundaries and have increasingly become preoccupied with "zones formed through the circulation of technical practices and devices" (Barry 2001, 3). This is by no means a new trend, but a number of new features can be identified which have increased the effectiveness of marketing products to consumers, as well as made their consumption easier and more attractive. In this introductory chapter, I would like to highlight some of the important strands and themes which have emerged out of our meetings, discussions and the subsequent texts in relation to genetic self-testing and cross-border medical treatment.

Consumers and the market for health

The notion of consumer medicine may appear as a recent phenomenon, but from an historical perspective the roots of advertising to consumers goes back at least three-hundred years. In many ways the notion of consumer medicine is related to the acceleration of the movements of goods, services and patients across various borders and territories, which have been traditionally understood in political terms. Increasingly, however, new technologies, such as the internet, help to transcend such boundaries creating new areas of operation that are more challenging to govern and regulate. This movement of materiality requires, however, various systems through which information is disseminated about products and services and thus makes them visible to the consumer. At the same time, increased interest has focussed on the 'creation' of the 'expert' or 'informed' patient whose autonomy and independence has been seen as an important development in the transition from what some have called paternalistic progressivism towards medical modernization (Brown and Zavestoski 2004; Fox et al. 2006).

Although the internet has accelerated and provided new opportunities for advertising products and services, this phenomenon is by no means new. For example, in 1708 the first advertisement for a medication appeared in an American newspaper (Young 1967), starting a trend that has refused to abate, but rather has increased in its scope and volume. This advertisement can be seen to mark the

beginning of what Wilkes et al. (2000, 112) have described as the development of a "symbiotic relationship" between the drug industry and the press; starting in the 1800s the drug industry began to spend larger and larger sums of money for advertising, and newspapers received an increasing amount of their income from these ads. Young notes, however, that it was not until 1908 that the US Pure Food and Drug Act was put to use in prosecuting the producer of 'Cuforhedake Brane-Fude' remedy for making false claims in their advertisement (Young 1967, 3). A century later, the relationship between consumers and the producers of medical services and products remains mediated to a large extent through different forms of media, such as the internet, and the claims that companies and researchers make concerning their products and innovations also remain the focus of contention, as well as trouble for consumers and regulators alike.

Advertising has, however, focused for a long time on health care professionals, in that it was through physicians, for example, that pharmaceutical companies were able to sell their drugs. It was not until the 1980s that drug companies also began to target the public through advertising in an attempt to better "educate" the lay consumer (Wilkes et al. 2000, 113). Some commentators have also noted that many governments, such as India and Cuba, have made concerted efforts to bolster their foreign tourism by supporting medical tourism within their national borders. In Malaysia, for example, the government has even gone as far as making medical tourism an official government policy (García-Altés 2004, 264). These activities can be seen within a broader political framework where the provision of national health care services to foreign nationals is developed within national economic policy frameworks. Many countries, especially in Asia, have worked to develop local or regional medical hubs that cater specifically to patients travelling from abroad to receive various forms of medical treatment (Choo 2002, 1004). This reflects a movement which is not just industry driven, but supported by national economic policies as well.

Despite the introduction of restrictive legislation both in the US and the EU, the use of advertising, educational material and different forms of media, such as the internet, continue to play an increasingly important role in the development of consumer medicine. In the US, the pharmaceutical industry is seen to wield a great deal of influence over policy making and some have argued that the increasingly high costs associated with the pharmaceutical industry are more related to lobbying than investments into research and development of new drugs (Angell 2005). At the same time, the interest to attract patients to different parts of the world to receive medical treatments and procedures has helped create a market for human tissue in various forms. Nelkin and Andrews (1998) note that cord blood can be used in shampoos, cosmetics and skin care products, which make it of great value commercially. Long hair can also be collected during haircuts for use in wigs for cancer patients who have lost their hair during treatment. The market for human body parts used in medical treatments goes, unfortunately, much further, creating space and opportunity for illegal and ethically questionable activities, such as a global traffic in human organs (Scheper-Hughes 2000), which is directly linked to the demand for such products by wealthy patients. As Andrews and Nelkin (2001, 27) have noted "[t]he market mania encourages actions that violate body integrity, exploit powerless people, intrude on community values, distort research agendas, and weaken public trust in scientists and clinicians."

Whether or not "the market" is to blame for questionable activities related to commercial healthcare services or the lack of regulation is difficult to gauge. Some commentators have argued that when the possibility of *selling* blood, for example, is added to the voluntary systems of blood

donation, one is merely expanding the range of choices made available to the individual (Arrow 1972, 350). It is clear, however, that the role that choice has come to play in these developments serves as an important undercurrent fuelling the challenges faced by patients and regulators alike.

If advertising new products and services can be seen as one important driver of this industry then the increasingly important role that patients and patient organizations are taking in the provisions of services, care, as well as research can be seen to form another important component as well. Recent trends within healthcare to strengthen the role and autonomy of patients can be seen as an important change within the patient-physician relationship, in that increasingly the patient is expected and encouraged to be active in assuming responsibility over ones health and care. Some commentators have argued, for example, that biomedical discoveries related to the genetic causes of disease gives rise to new forms of sociality, where ones genetic conditions help to define ones associations with certain groups (Novas and Rose 2000). At the same time patient organizations are playing an increasingly important role in mobilizing resources for research, as well as the formulation of national and supranational policies (Novas 2007). The information and support provided by patient organizations can be seen as an increasingly important avenue through which patients and their family members receive information and support for their conditions. At the same time numerous companies are offering services to people through which they can receive information on their genetic make-up and possible risk factors.

These changes can be seen to direct our attention also to the information that is made available to patients and who can be seen as the legitimate producer and disseminator of such information. Various information sources – besides patient organizations - which provide information over the internet, for example, are an important avenue through which various companies are providing "educational" information to potential customers. It remains difficult, however, for many patients of serious illnesses and diseases to be able to evaluate the "neutrality" of this information and to what extent it is based on existing evidence. This places patients and their family members at a disadvantage when searching for information on their condition.

Biotechnology policy and healthcare

Supranational and national policies can also be seen as another important element in the development of consumer medicine in that increasingly the products and services related to biotechnology are expected to form the basis for future economic development. As the European Commission has noted in a recent document:

> "Life sciences and biotechnology are widely recognized to be, after information technology, the next wave of the knowledge-based economy, creating new opportunities for our societies and economies." (European Commission, 2002, 7)

It is not surprising then that policy labels such as the knowledge-based bio-economy (KBBE) (European Commission, 2005) have more recently been put forward as a new policy rubric under which the economic, social and environmental potential can be reached through a more focused policy agenda. At the same time, however, the goals of scientific knowledge production are becoming increasingly intertwined with the knowledge-based bio-economy policies associated with biomedical research. As Häyrinen-Alestalo (2007; 2006) has noted, this represents an increased

penetration of political expectations into theoretical explanations associated with scientific knowledge production and its perceived role in society and economic growth.

These economic policies, however, reflect a tension between the commercial expectations that are associated with biotechnology and its various applications and the role of the nation-state and supranational organizations have in the regulation of such activities, as well as the provision of healthcare services to its citizens. On the one hand states are increasingly emphasizing the role of the private sector in providing goods and services in healthcare, but on the other hand they are also trying to govern and regulate the use and applications of new technologies, as well as maintain sovereignty, as well as control of costs within public healthcare infrastructures, particularly in the Nordic welfare states. The development of common markets and its implications to national healthcare services are not clear cut in that policies dictate that there should be free movement of goods and services.

At the same time, however, states are faced with the situation that not all practices across these national borders meet the same criteria or standards in any given country. This tends to result in inequalities and differences between countries as to what is offered, at what cost and under what legal jurisdiction. This tension is evident in many of the recent problems that governments and local officials in the Nordic countries face in trying to develop policies through which they are able to manage and regulate various activities related to the provision of healthcare goods and services. The movement of patients across borders to receive services is just one example related to this. The tension between public and private is not just a matter of international movement of patients, but can also be witnessed within countries in the tensions that emerge when patients receive treatments from private clinics and then go to public hospitals to deal with any possible resulting complications. The question of who is responsible for these costs (the patient, the private clinic or the tax payer) emerges as an important question in how to govern new technologies and their provision to consumers. Indeed, many new technologies, such as genetic self-testing challenge the traditional authority of the nation-state in that such services can be purchased over the internet.

The application of policies which encourage the development and application of new technologies is certainly going to continue, but the tools with which the ethical issues related to their consequences remain under development. Some authors have argued that the logic associated with care operates under very different mechanisms as opposed to the logics associated with markets and that the notion that the emancipation of the patient leads to equality is in effect misleading (Mol 2008). As noted earlier, the notion of the patient as a consumer is not a new one in that medical services and cures have been targeting patients for a very long time. One could argue, however, that what has emerged as an interesting development in the relationship between consumers/patients and the producers of various products is the degree to which such developments are linked to a positive view in the relationship between consumption and one's own health. Health and healthcare is to a lesser extent being mediated through the physician and to a greater degree through a private industry that creates images of good health and continually constructs and develops the individual's notion of what is and should be good health (cf. Helén 2004).

Patient expectations/political expectations

An important driver in this recent development is related to expectations and hope. Expectations and hope can be seen to operate at two levels; the political and the personal. On the political level

expectations derive from the economic and scientific potential that research and development are expected to produce. The significance of science and technology policies in driving expectations cannot be underestimated as policies play an important part in structuring actions. At the personal level, the need and desperation to find a cure or treatment for a life threatening or serious condition is also very powerful. As noted above, the role of patient organizations has come to play an important role in structuring and formalizing patient activities.

The notion of expectations and hope has come to be studied under the rubric of sociology of expectations (see Brown and Kraft 2006). According to Borup *et al*. (2006: 285-286), "expectations can be seen to be fundamentally 'generative', they guide activities, provide structure and legitimation, attract interest and foster investment. They give definition to roles, clarify duties, offer some shared shape of what to expect and how to prepare for opportunities and risks." In this sense the development of national policies to attract medical tourism and the need to find ways of curing or treating serious illness are related through the common thread of hope and expectations.

The emerging configurations through which R&D funding and medical services are mobilized and provided is increasingly premised on what can be described as a commercial paradigm that is generated through the creation of hope and expectations in science and technology policies, as well as the way in which the private healthcare sector is seen to take over many of the traditional responsibilities attached to the Nordic welfare state (Tupasela 2007; Tupasela 2006; Helén 2004; Brown, 2003). The problem remains, however, in the evaluation of what goods and services have some type of validity in relation to their ability to improve the health of people. The move towards market-driven healthcare appears in some senses to undermine the efficacy of public healthcare policies. This question can be asked in relation to genetic self-testing: what type of new information will I gain on myself, how will this improve my understanding of my health, and will it have a significant impact on people's health in general?

From genetic self-testing to 'medical tourism'

The chapters in this volume cover a host of issues in relation to genetic self-testing and 'medical tourism'. The volume is divided into two sections which deal with these issues, respectively. The first section covers four presentations which dealt with ethical issues relating to genetic self-testing.

In the first chapter Ástríður Stefánsdóttir focuses of five problems she sees associated with the sale of genetic information. Most notably she raises concerns over the uncertainties related to the accuracy of tests and whether they meet international standards associated with providing health information. She also questions the negative effect the tests might have on the public healthcare system, as well as the lack of supervision by a physician.

Anders Nordgren looks at the rhetoric that consumer genomics companies use in advertising their tests. According to Nordgren, genomics companies appeal to two general areas in their advertising; personal identity and personal empowerment. He argues, however, that information on one's own genetic makeup provides only a limited picture to personal identity and empowerment and that further work must be done to reduce the risk of inadequate information which may lead to misunderstanding.

Robin Engelhart's approach to genetic self-testing is more personal and hands-on. By taking a test himself, Engelhart is able to identify a number of ethical problems that people may be faced with if they take such tests. An important critique that Engelhart raises relates to the way the risk figures change over time, as new data becomes available on the role that different genes play in the probability of certain conditions and diseases. The fluctuations in risk figures over time raise a number of concerns as to the accuracy and significance of risk estimates and the role of association in predicting onset.

The final chapter in the first section by Frances Flinter describes how the UK's Human Genetics Commission (HGC) has reacted to the selling of genetic self-tests. Although not a regulatory body, the HGC plays an important part in the UK by providing guidance and advice to decision makers and acts as a sounding board to various stakeholders and the public. Some of the concern of the HGC relate to the quality controls that are adhered, the need to have a physician involved in all predictive testing, to as well as the clinical validity of these tests.

Together these chapters identify a number of problems associated with genetic self-testing as it relates to the notion of consumer medicine. The idea that commercially offered services, in some way, empower people is problematic in light of the validity and significance of the information that they provide. At the same time, however, genetic tests have the potential to provide important information to patients given that the information derived from them is valid and the process by which people receive it is also supported in some way by a healthcare professional.

The chapters in the second section are comprised of papers based on presentations which covered the topic of medical tourism – a term which people felt was misleading in that most often the reason to travel has very little to do with tourism, but rather with necessity.

In his chapter Niklas Juth explores the question of health care using the notion of justice. He begins this process by asking according to what principle(s) should health care be distributed and what types of problems may arise from medical tourism in relation to the notion of justice. He concludes that medical tourism can give rise to three types of problems: undermining the quality of health care for those in worse off countries, the loss of health care professions and finally those seeking medical treatment abroad receive treatment that is not legal or allowed in their own country.

Villy O. Christensen provides an important view-point to the discussion on medical tourism, namely that of the patient who is in need of treatment. Christensen asks a simple yet poignant question wouldn't you do the same if you were facing such a situation? He points out that few patients travel abroad with tourism in mind. Christensen argues that the unwillingness of national authorities to reimburse patients for receiving treatments - that are proven and legal abroad - is in many cases problematic and places patients in difficult situations.

Guido Pennings and Heidi Mertes examine the question of cross-border medical treatment in relation to infertility patients seeking treatment abroad, or 'reproductive tourism'. They note that there are several reasons why patients travel abroad: treatment cost, treatment quality and the availability of treatment. They argue that countries that have restrictive legislation should not

intervene when patient's seek treatment abroad since this raises a number of practical problems which are difficult to resolve.

Ilpo Helén looks at the issue of cross-border medical care from two perspectives. First, he looks at changes in public health care in relation to the 'neoliberal turn' arguing that movements such as the New Public management have contributed to the changes that we are witnessing in public health care. Second, in order to understand mobility we need to see it in a broader context where there has been an increase in the movement of a multitude of various aspects related to medical care; knowledge, personnel and technology.

The final chapter by Sirpa Soini looks at these issues from a legal stand point. In the first part of her contributions Soini examines the challenges associated with regulating genetic self-testing, noting that such tests are both a service and a product at the same time. She points out that there are examples, however, whereby countries are able to limit and regulate the purchase and delivery of such products using customs services as a barrier if needed. In the second part of her chapter Soini looks at the regulatory problems associated with cross-border medical treatments, where national health care and social security systems must deal with the complications that patients may come by as a result of receiving treatment abroad.

All the chapters provide important perspectives on the challenges which face decision makers, consumers, patients, as well as companies in trying to manage and understand the trajectories involved in consumer medicine. Both genetic self-testing and cross-border medical treatment offer a number of opportunities, both for producers and consumers of goods and services. At the same time, however, a number of important questions arise as to the limits and regulations that should be in place to protect consumers and assure that the products and services that are being offered are of good quality and do not offer false or misleading information as to their efficacy or significance in helping patients and consumers.

The role of the state and supra-national organizations is by no means self-evident within this changing environment in that on the one hand, this process has been supported by these same authorities, and on the other hand, they are also trying to control and limit the extent to which it develops and undermines their sovereignty. This dual role has created tensions between the development of consumer medicine and the consequences that authorities must deal with as a result of this development.

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