Consumerism, Information and Drug Prescribing Governance (Pharmakon)

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KEY FINDINGS

How are pharmaceutical drugs consumed in the Internet age? What information does the public want about prescription drugs? Are members of the public purchasing pharmaceuticals via the Internet? Does the Internet undermine national laws on the promotion of pharmaceuticals by manufacturers? What are the consequences for the future on how to govern and regulate the promotion and use of pharmaceuticals?

RESEARCH FINDINGS

Through interviews and observations of Internet health consumer groups, the project found:

- New information technologies have increased information-sharing among consumers about prescription drugs

- The Internet has created an electronic market-place for the purchase of prescription drugs through 'e-pharmacies' that trade across national borders

- Consumers of pharmaceuticals range along a continuum from those accepting medical expertise to those acting as autonomous consumers.

- Many consumers and professional organisations have doubts about the validity of Internet data, and want some means to 'kite-mark' data

- Pharmaceutical governance in the Internet age has depended on a range of informal 'fixes' of existing codes and practices and small legislative changes

- In the UK, regulators have accepted an 'online consultation' with a doctor as an acceptable contact for the prescription of drugs

- The pharmaceutical industry is lobbying against bans on direct-to-consumer advertising of pharmaceuticals, as consumers can now access information from foreign web-sites

- Some pharmaceutical companies fund patient support groups to provide web information to members of the public

- More generally, the Internet may destabilise the governance of technologies

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An Internet revolution in pharmaceutical consumption

The Internet and World-wide Web have revolutionised pharmaceutical consumption, both in terms of opportunities for information retrieval and sharing, and through the development of an online market place. The global nature of the Internet means that consumers can easily obtain information about drugs from foreign web-sites, and use online pharmacies to purchase these without a traditional consultation with a doctor.

The research found a willingness among consumers to use information technology to access information and acquire pharmaceuticals. However, many consumers and professional organisations have doubts about the validity of Internet data, and want some means to 'kite-mark' data. Respondents also raised concerns over the safety of medicines purchased on the Internet and some indicated they would not use this route to acquire pharmaceuticals.

Motivations to use the Internet for pharmaceutical acquisition include privacy, an unwillingness to pass through a professional gatekeeper, cost and purposes for which drugs are to be used. In the UK, most drugs purchased from non-traditional sources are for 'lifestyle' conditions such as weight loss and erectile dysfunction, while elsewhere in the world many other drugs are now sold online.

We identified three 'moments' in the emergence of online pharmacy in the UK. The first employs Internet technology to facilitate electronic transfer of prescriptions from prescriber to pharmacist. Following a UK government pilot, this approach is shortly to be rolled out as an official technology development. The second is the fully-fledged online or e-pharmacy, in which non-prescription drugs (pharmacy medicines requiring qualified pharmacist supervision) are ordered online and dispensed by mail order. Here an Internet questionnaire completed by the purchaser is assessed by a pharmacist before medicines are dispensed. In the third moment, in what we call the e-clinic, an online consultation with a doctor generates a prescription which is then filled and then dispensed by mail order. This latter innovation establishes the 'online consultation' as a legitimate contact between doctor and patient for prescribing, and may have consequences for patient/doctor power balances.

NHS subsidy of prescriptions may place a cap on potential for UK growth in e-pharmacy in contrast with nations where drugs are purchased at market cost. Pharmaceutical companies expressed a desire to regulate overseas e-pharmacies that may sell bogus or counterfeit drugs to UK consumers.

Direct-to-consumer Advertising and the Internet

While web-based information on pharmaceuticals is legal, UK and EU law on direct-to-consumer advertising (DTCA) applies to pharmaceutical industry web sites, and multinational companies must observe UK law for their British web pages. The pharmaceutical industry argues that this is illogical and may affect competitiveness, and some companies have funded support groups to provide web information for patients. The UK pharmaceutical industry's professional association is lobbying for a change to DTCA legislation to permit more information to be provided to consumers legally.

The ban on DTCA was a sticking point in the emergence of UK e-clinics. Unlike US and other outlets, e-clinics here cannot provide information about treatments or prices before the online consultation. Only when a doctor has reviewed a patient's condition may the e-clinic recommend prescription pharmaceuticals. During the research we found that UK 'e-clinics' had negotiated an arrangement with regulators by which a doctor at the clinic would conduct an 'online consultation' with a potential consumer before providing any information about the pharmaceutical compounds that could be purchased. This circumvented the ban on direct advertising of pharmaceuticals to consumers, and were agreed with e-clinics under existing legislation.

Patient support groups have varied perspectives on DTCA. Some see dangers for consumers in relaxing regulation, while other consider benefits to their constituencies from flexibility on promotion and licensing drugs. Alliances have been built between some pharmaceutical companies and patient groups, and some groups provide detailed information on particular pharmaceutical products in return for financial aid from industry.

The Emergence of Online Patient Communities

In additional to the use of Internet technology by established patient support groups such as Breast Cancer Care and the MS Society, many new groups have emerged on the Internet using web sites and message boards to create virtual patient or consumer communities. These latter groups sometimes share information about how to obtain pharmaceuticals without a consultation with a licensed prescriber, often through Internet pharmacies. Some can be quite 'shadowy', as they challenge traditional ideas about health and illness.

Online patient groups contribute to the development of patient expertise in specific conditions. We studied three online communities that explicitly engaged with the use of pharmaceutical drugs to treat conditions from over-weight to erectile dysfunction. While these might be regarded as 'lifestyle' conditions, the research concluded that there is a continuum among those involved in using pharmaceuticals (sometimes for purposes not intended by manufacturers) from a medically-oriented 'expert patient' to an 'autonomous consumer' whose expertise may run counter to mainstream medical opinion. The Internet has facilitated possibilities for autonomous approaches to the use of pharmaceutical technology, and in one community, weight loss drugs were used to sustain anorexia: a condition generally regarded as a dangerous and pathological state. Such websites can be seen as subversive and have been subjected to persecution by other organisations.

A Model of Technology Governance

The research suggests a conservatism in how regulators govern pharmaceutical prescribing in the face of the radical challenge of new information technology. For both the emergence of the e-clinic and direct advertising to consumers, existing legislation and codes of practice have been used to regulate new practices, rather than bringing in new legislative codes to address the new challenges of the Internet. Pharmaceutical governance in the Internet age has depended on a range of informal 'fixes' of existing codes and practices and small legislative changes (for example, to permit electronic signatures on prescriptions).

We understand this as a desire within regulatory bodies to retain existing governance arrangements to manage information innovations rather than develop new legal and regulatory frameworks. Thus, governance can be seen as a dynamic process that establishes a working solution to contradictory pressures, for example, between public safety and individual freedoms.

The research found that governance is best understood as a never-ending effort to balance the interests of different 'stakeholders' including professionals, industry and consumers. These stakeholders form strategic alliances around specific issues concerning a technology, however these alliances are fluid. For instance, the UK pharmaceutical industry may support consumer requests for better information on pharmaceuticals, but resist online pharmacies, which they see as a means to market counterfeit pharmaceutical products

This model of governance of pharmaceutical technology may be generalised to other health technologies. In this model, governance is always in the process of 'breaking down' and emerges from alliances between stakeholders. Legal frameworks are less important than voluntary agreements and self-regulation, but the success of governance depends on stability in the environment. The emergence of new information technology may destabilise governance and lead to new patterns of use of a technology.

About the Project

The research was undertaken as part of the ESRC Innovative Health Technologies Programme and was conducted over a two-year period from 2002. The project used a range of data collection approaches including a wide-ranging review of published material on the topic of pharmaceutical consumption and a survey of web sites, electronic discussion fora and other manifestations of Internet-facilitated communication.

Given the topic area, it was inevitable that a major data collection approach would be a survey of Internet-enabled resources, and this method has been used throughout to research such aspects as e-pharmacy, support groups and stakeholders. An example of a search was to seek websites concerning lifestyle medications. We focused on specific conditions such as weight loss, erectile dysfunction and depression, and located websites that would provide drugs related to these conditions. The names of specific pharmaceuticals were entered into search engines to identify commercial web sites, information-providers and other links. From this we were able to develop a typology that was used subsequently in analysis and theory-building.

We conducted face-to-face, telephone and e-mail interviews with consumers, pharmacists, representatives of the pharmaceutical industry and regulators, both to gain background information and to explore the different perspectives on pharmaceutical consumption of the various stakeholders.

In addition to these methods, we applied the emerging data collection approach of 'online ethnography' on web-based patient support groups that use the Internet to enable members to discuss health-related issues. This involved observation of the discussions, direct participation via the forum and subsequent interviews with participants using e-mail. Despite the lack of direct engagement with participants as in traditional observation, the mix of textual analysis, prolonged participant observation and qualitative interviews can provide valid and reliable data. Using these approaches our researcher subscribed to three message forums that we considered would enable us to understand the range of patterns of consumption. She announced her presence as a researcher, and after a time to learn the norms and values of the groups, used the forums to ask questions of participants. Some participants responded to the questions via the forum, while others chose to email their responses privately, often leading to subsequent in-depth interviews by e-mail.

The data from the study has been analysed to explore a range of aspects of pharmaceutical consumption, the emergence of e-pharmacies and e-clinics and challenges to how pharmaceuticals are governed. Further research on health technology governance is now planned.