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**Respectable Deviance? Negotiating the opportunities and risks in online  
medicine purchasing**

by

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Thesis for the degree of Doctor of Philosophy in Web Science

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# **ABSTRACT**

FACULTY OF HEALTH SCIENCES

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## **RESPECTABLE DEVIANCE? NEGOTIATING THE OPPORTUNITIES AND RISKS IN ONLINE MEDICINE PURCHASING**

Lisa Sugiura

This thesis explores online medicine purchasing and provides insight into how people account for this activity via the application of the concept of respectable deviance. Drawing together established deviance theories; respectable deviance considers the construction of online medicine purchasing, the justifications presented to challenge how it is labelled, and how the behaviour is managed. Those purchasing medicine online are not necessarily criminalised, however, the behaviour has been constructed as risky. This is because people can buy medicines that traditionally require prescription from registered practitioners. These new opportunities to purchase illicit medicines have implications for the pharmaceutical marketplace, regulation and governance, and healthcare expertise. The specific risks associated with online medicine purchasing, namely counterfeit medicines, criminal activity, and health implications, merge with the challenges to the marketplace, the challenges to regulation and governance, and the challenges to healthcare expertise. People purchasing medicines online acknowledge these ‘risks’, and redefine them in terms of justifications. Utilising an interpretivist mixed-methods study encompassing forum observations, online survey, and interviews, this research allows an understanding into how those engaging in ‘risky’ behaviour breaking with accustomed practices (i.e. purchasing prescription/ unauthorised medicine online), manage their performances with techniques of neutralizations, specifically challenging governance and medical expertise. At the same time, as the Web provides a space for deviance, it also provides a space for people to manage how their actions are perceived. Respectable deviance highlights how people respond to the unique risks and opportunities afforded in online medicine purchasing



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# DECLARATION OF AUTHORSHIP

I, Lisa Sugiura

declare that the thesis entitled

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and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- parts of this work have been published as:
  - Sugiura, L., Pope, C. & Webber, C. (2012). *Buying unlicensed slimming drugs from the Web: a virtual ethnography*. In: the proceedings of the Web Science Conference 2012, Chicago, US, 22 - 24 Jun 2012, 4pp.

- Sugiura, L., Pope, C., Weal, M. & Webber, C. (2012). *Observing Deviancy Online*. In: the proceedings of the Digital Research Conference 2012, Oxford.
- Sugiura, L. (2013). *Public and private faces in web spaces – How Goffman’s work can be used to think about purchasing medicine online*. In: the Working Papers on Health Sciences Journal, Aug 2013.

• Signed: .....

Date:.....

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# Abbreviations

AoIR - Association of Internet Researchers

ARTG - Australian Register of Therapeutic Goods

ASBO - Anti-Social Behavioural Order

BERA - British Educational Research Association

BPS - British Psychological Society

BSA - British Sociological Association

BSC - British Society of Criminology

CASRO - Council of American Survey Research Organisations

CDAPCA - Comprehensive Drug Abuse Prevention and Control Act

CDSA - Controlled Drugs and Substances Act

CMC - Computer Mediated Communication

CSA - Controlled Substances Act

DA - Drugs Act 2005

DEA - Drug Enforcement Administration

DPA - Data Protection Act 1998

DoH - Department of Health

EEC - European Economic Community

ECHR - European Convention on Human Rights

ED - Erectile Dysfunction

FDA - Federal Drug Administration

FDA - Food and Drugs Act

FFDCA - Federal Food, Drug, and Cosmetic Act

GBCS - Great British Class Survey

GBL - Gamma-butyrolactone

GPhC - The General Pharmaceutical Council

HCP - Healthcare Professional

HMR- Human Medicines Regulations 2012

HRA - Human Rights Act 1998

HTML - HyperText Markup Language

HTTP - Hypertext Transfer Protocol

IM - Instant Messenger

INTERPOL - International Criminal Police Organisation

IRB - Institutional Review Board

MDA - Misuse of Drugs Act 1971

MHRA - Medicines and Healthcare Products Regulatory Agency

MOOC - Massive Open Online Course

MRA - Market Research Association

NABP - National Association of Boards of Pharmacy

NDA - New Drug Application

NHS - National Health Service

NICE - National Institute for Clinical Excellence

NLP - Natural Language Processing

NPS - Novel Psychoactive Substances (“Legal Highs”)

NRES - National Research Ethics Service

OTC - Over-the-Counter Medicine

PDMA - Prescription Drug Marketing Act 1987

RGO - Research Governance Office

RPSGB - Royal Pharmaceutical Society of Great Britain

SPSS - Statistical Package for the Social Sciences

TGA 1989 - Therapeutic Goods Act

TMA - The Medicines Act 1968

URL - Uniform Resource Locator

VIPPS - Verified Internet Pharmacy Practice Sites

WHO - World Health Organisation

WWW - World Wide Web



# 1. Introduction

This thesis considers the concept of respectable deviance in relation to online medicine purchasing. Although this consumer behaviour is not necessarily criminalised, it is constructed as risky because people can buy legal medicines that would normally be prescribed by a registered practitioner. They can also obtain drugs that would be categorised as illegal if bought on the street, in person, in the offline world. While procurement and consumption of pharmaceuticals and illicit drugs has always been an issue of authoritative concern and control, the Web as a 'new' digital means of obtaining medicines is becoming subject to attention by regulators and law enforcement because it offers opportunities to purchase illicit medicines as well as drugs. In providing unrestricted accessibility to medicine purchasing, the Web has democratised consumerism. It allows more people than ever before to engage in illegal and deviant activities. At the same time, as the Web provides a space for this deviancy, it also provides a space for people to manage how their actions are perceived. Whereas troublesome adolescents (Pearson, 1983) and the 'underclass' (Murray, 1990) had few ways to combat the deviant label, purchasers of medicine –legal and illicit – can use the Web as a place to justify and manage their behaviours and deflect such labelling.

This thesis rests on literature and theory from different disciplines, including criminology, sociology, law and health science. The research explored debates and defined schools of thought, each of which have merits but also limitations when applied to the issue of purchasing medicine online. In undertaking interdisciplinary Web Science (Halford et al., 2010) research, this study makes transparent that which the Web renders opaque, namely how individuals manage online medicine purchasing, and it shows how the Web has helped create novel forms of deviancy. This thesis explores the practice of online medicine purchasing, from the perspective of web users. It moves beyond the headlines<sup>1</sup> and warning campaigns to contextualise the provision of medicines

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<sup>1</sup> Although there are 12 years between them, the newstories below are both concerned with the association between fatalities and medicine bought online. These are without a doubt tragic cases and are extreme examples of the 'risks' of purchasing medicine from the Web. <http://news.bbc.co.uk/1/hi/england/3130187.stm>  
<http://www.theguardian.com/lifeandstyle/2015/apr/26/should-i-buy-prescription-drugs-over-internet>

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online, and provides a description of this practice and subjective accounts of purchasing medicine from the Web. It will show how the framing of risks and deviance is challenged, and explore how online medicine consumers consider their actions.

### **1.1. The problem of online medicine<sup>2</sup> purchasing**

Before the Web there were limited options for people to purchase medicine<sup>3</sup>. People can now choose to visit a doctor or pharmacy or go online to obtain medicines.<sup>4</sup> Amongst the plethora of items available to buy on the Web, medicine is just one. However, buying medicines online has been problematised; it is portrayed as a risky thing to do.

Online shopping has been a feature of the Web since the late 1990s and has become ubiquitous (Pew, 2008). It is possible to purchase anything from the Web<sup>5</sup>, including controlled and regulated medicine and drugs. Concerns about the dangers of online medicine purchasing were first raised towards the end of the 1990s, following revelations that prescription medicines were available to purchase without any doctor patient interaction (Bloom & Lannacone, 1999; Henney et al., 1999). Concerns about counterfeit medicines in the online pharmaceutical trade soon followed (Bessell et al., 2002). Legislation that pre-dates the Web exists to protect patients from harm resulting from unsafe medicines and from illicit medicine and pharmacy practices. However, the sale of medicines online makes it easy to bypass these risk-management systems.

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<sup>2</sup> The terms medicine and drug are often used interchangeably. For the sake of clarity from the outset, in this thesis the term medicine will be used to refer to substances that can be legitimately prescribed or obtained. The term drug will be used when it occurs in quoted texts and data, and to refer to substances prohibited by law (e.g. heroin, ecstasy). A full explanation of terms is included in the glossary.

<sup>3</sup> Mail ordering of medicines is acknowledged as pre-dating the Web; however, this was not globally adopted, and was more popular in the US than the UK for example (see Gregory & Munro, 1991). Generally herbal or complimentary medicines are offered for sale, which are not the main focus of this research.

<sup>4</sup> Over the Counter medicines are also available to purchase from supermarkets. These could be bought from without any interaction with a healthcare professional long before the Web, however, the key difference is that people are only allowed to buy two packs at a time, although there is nothing stopping people from going to multiple outlets if they want to obtain larger quantities.

<sup>5</sup> The term web denoting the World Wide Web is used in this thesis rather than the Internet, although the latter is used in a great deal of academic literature. This is because this research has a specific focus on the impact that the Web has on society (and vice versa) since its implementation in 1991. It is the Web via the interlinked document pages – web pages, that provides the means to purchase goods, although these are accessed through the Internet. The introduction of the Web has seen a substantial expansion in use of the Internet, paving the way for continued commercial and institutional exploitation and utilisation (Lee, Fielding and Blank, 2008).

There are some specific risks associated with buying medicine online. These involve the quality of the medicine, challenges to authority and legislation, and the risk of harm. In addition there are concerns about fraud and theft associated with online consumerism. On the one hand, the Web offers a range of benefits to consumers (for example ease and accessibility of products, lower prices, greater choice) yet on the other it is a site of risk and harm. Concerns about the risks of online medicine purchasing have received some attention in the media, policy and research, but this thesis sets out to examine this issue from the perspective of the online medicine purchasers and understand how they perceive and manage their behaviour in spite of the purported dangers.

Criminological theory explains that the labelling of certain behaviours can have an effect on both the individuals concerned and wider society (Becker, 1963). Actions perceived as risky are not necessarily risky in themselves or even considered risky by those doing them, but are often labelled as such. The ways that people frame their behaviours as risky or non-risky impacts on how they present themselves to others (Beck, 1992; Giddens, 1990). In this thesis, I argue that people manage their behaviour and present themselves differently when discussing their online medicine purchasing, because external agents have socially constructed the purchasing as a risky behaviour. There has been a cultural labelling of such purchasing behaviour, purchasers are shaped and are negotiating their behaviour (and presentation of self) in light of that labelling.

In the remainder of the chapter, I outline a typology of medicine purchasing and provide a conceptualisation of the Web. An outline of the way medicines are regulated and professionally administered 'offline' provides background and context for the study. To understand the role of the Web in obtaining medicine the relationship between online spaces and offline lives needs to be explored. I argue that to understand how the Web shapes consumerism, we must also conceptualise the Web as an information source and a place where people connect with others in networked societies (Castells, 1996).

I then outline online medicine purchasing, including the different opportunities available online, and how orthodoxy can be challenged, along with the debates over medical provision online. I show how issues associated with online medicine purchasing have been framed as risks and outline the theoretical

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approaches that have informed my use of the concept of respectable deviance. The critical perspective that I have taken draws on the interpretivist paradigm, in particular the work in the late 1950s and 60s of Becker, Goffman, Sykes and Matza, which is informed by social constructionism and symbolic interactionism. This builds on some of the early interpretivist work of Katz and the more recent development of cultural criminology (Ferrell, Hayward and Young 2008; Webber, 2007). I follow the description of the theoretical approach with the research questions and the aim and scope of the project, along with an explanation of how Web Science can offer a unique insight into the study of online consumer health behaviour. I then outline my contribution to knowledge by describing the theoretical, methodological and practical importance of this thesis. To conclude I outline the thesis chapter by chapter.

### **1.2. A typology of medicine purchasing**

The global regulatory landscape for medicines is continuously evolving. Regulators have to respond to new medicines and technologies, as well as policy and practice changes. Regulatory bodies take responsibility for overseeing particular aspects of healthcare, including the safety of medicines. They are the recognised authorities in their field and their role is to protect and improve public health. Public compliance is therefore vital in ensuring the success of regulators. Although the different regulatory agencies and their roles are not being explored in this thesis, I will briefly address the UK regulatory agency.

In the UK the Medicines and Healthcare products Regulatory Agency (MHRA) is the government agency, which assesses the safety, quality and effectiveness of medicines, and authorises their sale or supply for human use<sup>6</sup>. The MHRA carries out the operations of the licensing authorities under Section.6 of the Medicines Act 1968. They create benefit-risk profiles for medicines and provide this information to the public. Web crawling software has also been configured by the MHRA to monitor for websites immersed in the illegal advertising, supply and distribution of medicines. The software recognises sites that

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<sup>6</sup> <https://www.gov.uk/government/organisations/medicines-and-healthcare-products-regulatory-agency>



appear to be UK hosted, managed or located. Products are then purchased, tested and in appropriate cases enforcement action is taken to remove the offending site, along with prosecution of those responsible. In addition the MHRA works alongside the police, ISPs, credit card companies and other relevant stakeholders to terminate illegal Internet activities, including those based overseas. The MHRA has also successfully worked with international partners to tackle counterfeit and substandard products from entering the supply chain. This will be spoken about more in the context of the online pharmaceutical trade, in chapter three. The MHRA also attempt to educate the public about the benefits and risks of medicines, although as this thesis will later show, certain campaigns have not been that successful in dissuading people from purchasing medicine online.

As a starting point to contextualise medicine purchasing, the UK regulatory framework will be discussed. In this thesis, regulation encapsulates nation/state medicine laws and licensing – the ‘rules’ to obtaining medicine legitimately. In the UK, medicines can be supplied in a number of ways. Some can be purchased at supermarkets; others can only be obtained from a pharmacy. Some require a prescription, issued by a qualified healthcare professional, and traditionally this prescribing has been tightly controlled by and limited to pharmacists and medical doctors. It is only recently that UK nurses have been provided with the authority to prescribe independently (Latter et al., 2007)<sup>7</sup>. The Health and Care Professions Council provides a useful summary of the prescribing rights of different healthcare professionals in the UK.<sup>8</sup> In the remainder of this section I address the key aspects pertaining to the sale and supply of medicines in order to provide a typology of how they are (legitimately) purchased. The main areas to consider are licensing, legislation, and global issues.

Regarding licensing, all new medicines are assessed to ensure that they meet the required standards in pharmaceutical testing and clinical trials. In the UK, this is overseen by the MHRA<sup>9</sup> and supported and guided by the National

---

<sup>7</sup> In the UK until 1992, only doctors and dentists were authorised to prescribe. The introduction of the Medicinal Products: Prescription by Nurses Act 1992 allowed certain specially qualified health visitors and nurses to prescribe.

<sup>8</sup> <http://www.hpc-uk.org/aboutregistration/medicinesandprescribing/>

<sup>9</sup> <http://www.mhra.gov.uk/Howweregulate/Medicines/Inspectionandstandards/Medicinestesting/>

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Institute for Clinical Excellence (NICE<sup>10</sup>). In the US, the Federal Drug Administration's (FDA) drug review process plays a similar role<sup>11</sup>. Inspection and testing continues throughout the lifetime of the medicine. Product labels, leaflets, prescribing information and advertising are also checked to meet the standards required by regulations. Medicine licenses can be withdrawn, but unlicensed medicines may sometimes be prescribed to patients (for example, some medicines have been trialled and licensed for use with adults but are not licensed for use by children). Some unlicensed medicines have not undergone clinical tests for safety and efficacy.

Current UK medicines legislation is collected in the Human Medicines Regulations 2012,<sup>12</sup> which encompasses approximately 200 statutory instruments, including the Medicines Act 1968,<sup>13</sup> which govern manufacture, provision and supply. The Medicines Act 1968 defines medicines in three ways:

- prescription-only medicines, which can be obtained from qualified prescribers (e.g. doctors, dentists, nurses or pharmacists)
- pharmacy-only medicines (known colloquially as “over-the-counter” (OTC) medicines)
- general sales list medicines which can be obtained without a prescription.

This regulation does not take purchase into account, and only applies to sale and supply. UK medicines regulation does not apply to drugs that are classified as illegal under the Misuse of Drugs Act 1971. This statute covers the non-medicinal use of drugs and criminalises the possession and trafficking (supply, intention to supply, import/export, production) of controlled drugs. These drugs are classified into classes A-C in accordance with perceived levels of harm, and schedule 1-5 relating to ease of access. These classifications have been subject to criticism from Nutt et al. (2010), who have flagged up concerns about the relative arbitrariness of the measures of harm that form the basis for the classifications.

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<sup>10</sup> <http://www.nice.org.uk/mpc/index.jsp>

<sup>11</sup> <http://www.fda.gov/drugs/resourcesforyou/consumers/ucm143534.htm>

<sup>12</sup> [The Human Medicines Regulations 2012](#)

<sup>13</sup> <http://www.legislation.gov.uk/ukpga/1968/67/contents>

UK consumers therefore, have legal access to medicine via the following mechanisms:

1. (Via prescription) To purchase prescription only medicine the consumer needs a valid prescription issued by a licensed healthcare professional. These must be dispensed by a registered pharmacy. Obtaining prescription medicine without a prescription is therefore illegitimate, as there is no threat of prosecution yet the action is unauthorised.
2. (Non prescription) To purchase pharmacy only medicines (OTC) a prescription is not required but a pharmacist should be consulted before purchase. These are usually sold in licensed outlets (e.g. products containing stronger ingredients such as codeine i.e. Solpadine).
3. (Non prescription) To purchase general sales list medicines a prescription is not required and these are available for sale from a variety of outlets, not just pharmacies (e.g. paracetamol).

There are complicated global differences in medicine regulations within countries and regions (Scaria, 2003). For example, in the US medicines are classified into two categories: prescription and OTC. Although prescription medicines require a prescription similarly to the UK, in the US OTC medicine does not require a consultation with a pharmacist. In Europe, pharmaceutical companies are prohibited from directly advertising medicines to the public, but are allowed to do so in the US<sup>14</sup>. The way people find out about medicines is therefore different in different countries. This is further complicated by the advent of online purchasing.

According to European Law the sale of prescription only medicines on the Web is prohibited as per Directive 2001/83/ CE requirements, which state that online sales of non-prescription medicine is allowed only if they are authorised and sold by a licensed pharmacy. From a EU wide and a national perspective, regulation applicable to the legal sale of online medicines was implemented in Directive 2011/62/EU by Legislative Decree n.17, of 19 February 2014. This regulation considers remote sales to the public including pharmaceutical products via the Web. From July 2015 online pharmacy sites trading out of EU

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<sup>14</sup> Council Directive 1992/28/EEC of 31 March 1992 on the advertising of medicinal products for human use. (Articles 1(3) and 3(1).) *Official Journal of the European Communities* No L 1995 11 February:32/26.

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member states must follow a model as described in the regulation, whereby a recognisable logo is utilised.

The absence of standardised international regulations means that policing and control of the movement of medicines across borders is problematic. The Web allows people to view websites outside of national and legislative jurisdiction and enables access to unregulated and unauthorised substances within the home country sent from abroad.

### **1.3. Conceptualising the Web**

The problem with medicine purchasing online is that the Web appears to be ungovernable. To understand the implications of this we need to explore what the Web is. However, understanding what the Web is as opposed to how the Web operates is problematic as the two are synonymous. It is a socio-technical phenomenon (Halford et al., 2010). The Web is built on top of the Internet (Ackland, 2013). The Internet is a large distributed network of computers initially developed by the US military in the 1960s<sup>15</sup>. The original World Wide Web implemented by Tim Berners-Lee whilst based at CERN, and publicly released in 1991, is a massive distributed network of resources, including documents, images and sounds across that network. The protocol that governs the Web is the HyperText Transfer Protocol (HTTP). This allows a coding language - HyperText Markup Language (HTML) to create web pages, which are used to access information on the Web. While the Internet is a network of computers connected by physical wires, the Web is a diverse, complex system of networks, where humans are able to create, communicate, browse and consume information and services (Hendler et al., 2008). These networks are not just computer or document networks, but networks of people. Halford et al. (2010) claim that the Web is co-constituted, as the technology shapes society and society in turn shapes technology. The World Wide Web that we have today is more than the exponential amount of data; it is the result of how society has used and shaped it.

There is often confusion between the Web and the Internet. Web 2.0 (O' Reilly, 2009) is the term used to describe the second generation of the Web, which

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<sup>15</sup> The Internet was developed with funding from the Defense Advanced Research Projects Agency (DARPA).

focuses on user collaboration and the sharing of online information, associated with social media, such as Facebook and Twitter. However, the Internet hosts Facebook and it works using the Web's http protocol, yet search engines are unable to access its content. This has led Berners-Lee to argue that Facebook (and other closed networks) is "not the Web" (Berners-Lee, 2010).

According to Castells (2011, 1996), the architecture of contemporary societies are comprised of networks. Social and media networks are shaping the most important structures today. This *network society* is a society where the fundamental social structures and actions are coordinated around digitally handled information networks. The network society involves social networks that process and administer information using electronic technologies (Castells, 2011, 1996).

The Web has transformed business, work, consumerism, leisure and politics (Ackland, 2013; Castells, 2001) and this era has been described as an 'information age' (Webster 2003). The Web has undoubtedly had a huge influence on social lives, particularly those living in the Western industrialised world and is regarded by some as the 'largest human information construct in history.'<sup>16</sup> Websites are digital spaces, and online interactions between people metaphorically occur within these virtual spaces rather than in the countries where individuals or website servers are located (Ackland, 2013). The Web as a globalised phenomenon challenges national laws: its unregulated spaces provide possibilities for criminal and deviant activities (Yar, 2006). The Web is global and not local and therefore it renders the regulation of medicine problematic.

The Web combines information, individuals and societies across the globe. These aspects make the Web a threat to governance and regulation, as can be seen in the case of purchasing medicine online. The Web provides opportunities to challenge power structures, but what is different about being online and how do web spaces encourage libertarianism? Annette Markham's (1998, 2003, 2007) analogies are useful to explore how people interpret being on the Web. These analogies are the 'Internet as tool,' 'Internet as place,' and 'Internet as way of being.' As a tool, the Web can be understood as allowing us

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<sup>16</sup> <http://webscience.org/>

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to conduct tasks more quickly and easily. Research into online illicit drug practices have theorised the Web as an information or purchasing tool (Barratt, 2011). As a place, the Web provides a location for communication and interaction. This can be understood through the term 'cyberspace,' a term envisaged by the science fiction writer William Gibson in his 1984 book *Neuromancer* as "*a consensual hallucination experienced daily by billions of legitimate operators... A graphic representation of data abstracted from the banks of every computer in the human system* (Gibson, 1984:69)." Cyberspace has been a popular term with academics to describe the Web as a virtual place where people interact (Smith & Pollock, 1999; Kitchen, 1998; Leissig, 1996, 1999; Turkle, 1996). As a way of being, the Web is amalgamated into everyday life (Barkardjieva, 2011; Wellman & Haythornthwaite, 2008) such that 'reality' is both offline and online.

This thesis considers the Web as a tool, place and a way of being in relation to online medicine purchasing. It is a tool or means for online medicine purchasing, but online spaces such as virtual pharmacies and health forums are also places where people visit and interact, and increasingly in allowing medicines to be purchased, the Web is part of everyday life. However, in the context of online medicine purchasing, the Web may challenge orthodoxy and hegemonic norms in society.

One of the biggest impacts the Web has had on society is in the area of eCommerce (Lauden & Traver, 2007). The Web allows the purchasing of pretty much anything online. Improved global access and diverse opportunities mean that online shopping has grown exponentially as the marketplace has responded to the potential of increased customers. Online consumers are able to benefit from increased information about the items they purchase, lower transaction costs and prices, and a wider choice of products than those available in the traditional economy (Adamic & Huberman, 1999). eCommerce has revolutionised how goods are supplied to consumers and the Web has transformed the drug marketplace, as there is an increased customer demand, which impacts significantly upon the supply chain. People are able to obtain drugs and medicines that are not supplied in traditional offline pharmacies, and are presented with strong economic incentives by online retailers. This exposes a weakness in regulating the distribution of pharmaceuticals. As the earlier discussion demonstrated, pharmacies are legally obliged to meet a

number of licensing requirements before they can trade legally in a large number of countries, and these also apply online. However, many online pharmacies take advantage of the global nature of the Web and forgo adhering to stringent medicine legislation. Traditional drug markets are thus expanded and diversified as the line between illegal and legal supply chains are complicated with the addition of illegitimate and legitimate online pharmacies. A more detailed discussion about the distinctions between these categories will be conducted in the next chapter.

Online forums dedicated to discussing health issues, social media and online blogs and magazines have further contributed to the promotion and selling of medicines on the Web (Lavorgna, 2014). In addition the Web provides new opportunities for obtaining information (Nie and Erbring, 2000) and health related information has been reported as one of the main reasons individuals use the Web (Eysenbach, 2001). A report published in October 2010 by the Nuffield Council on Bioethics, a Working Party set up in 2008, investigated the implications of people being encouraged to take more personal responsibility for their health. This report refers to figures published by the Office of National Statistics in 2008, which claimed that 34% of all UK Internet users have used it to seek health-related information, and to the 2009 Oxford Internet Survey (Dutton et al., 2009) which found that 68% of UK Internet users had searched for health information online. In addition, figures for other developed countries suggest that 70% or more of all users use the Web to obtain health-related information (ibid).

It is clear that the Web has created new routes for the discovery, supply and purchase of medicines. Flourishing eCommerce along with a regulation-less setting on the Web has enabled the growth of websites that market medicines (Scaria, 2003). The Web offers particular affordances (that is, functional and relational aspects which frame but may not determine the possibilities for action) and these are important in the new discourses surrounding buying medicine online. These focus on concerns that by bypassing the offline ways of procuring medicine, the Web challenges the pharmaceutical market, authority and medical expertise, and it is to these debates that the chapter now turns.

## **1.4. Key challenges posed by providing medicine online**

Medicine provision online challenges the pharmaceutical market, governance, and expertise. These threats have been framed as risks to the consumer and are encapsulated in three arguments about risk, centred on counterfeit medicines, criminal activity and health implications. I will explore these risks in depth in Chapter Three. The risk rhetoric is intertwined with discussions about how being online and the consumer healthcare opportunities provided enable people to threaten the profit of pharmaceutical companies, challenge the control of government and legislators, and dispute the expertise of healthcare professionals.

### **1.4.1. Challenges to the market: counterfeit medicine online**

There are on-going global public health debates regarding the battle for control over the pharmaceutical market. The monopoly of the pharmaceutical industry has been threatened by suggestions that patients should buy their medicine online to save costs (Tuffs, 2002). However, there are concerns over counterfeit and fake medicines being obtained on the Web. The international market of counterfeit sales has been valued at \$75 billion in 2009 (Wellcome Trust, 2009). Pharmaceutical companies maintain that purchasing medicine online is risky because the product may be counterfeit or substandard (Jackson et al., 2010).

The harm of counterfeit medicines, as opposed to other types of counterfeit goods (designer clothing for example), is seen as more significant as they are what Yar (2006) terms 'safety critical.' Counterfeit medicine may not be effective, or worse may be lethal. Newton et al. (2006) claim that in poorer countries, half of medicines used are fake and have little or no active ingredients. In richer nations fake medicines cause adverse reactions and some fatalities (Nordt et al., 2010; Okie, 2009). Patients everywhere are seen as vulnerable, as international trading in medicines escalates (Nordt et al., 2010).

The member states of the World Health Organization (WHO) established a working group in 2010 in order to determine the best strategy to tackle counterfeit medicine (WHO, 2011). However, this has proved rather problematic. It is complicated with issues of intellectual property rights (Mackey, 2013), and controversies about pharmaceutical pricing (Attaran et al.



2012). A particular area of contention involves the debate surrounding generic medicine<sup>17</sup>. It is suggested that anti-counterfeiting laws in some countries protect commercial interests over public health interests.<sup>18</sup> For example, in East Africa the reforms to anti-counterfeiting laws, supported by some pharmaceutical companies, threaten the availability of generic medicines, which many Africans rely on. Customs authorities have seized legitimate generic AIDS and cancer medicines in transit from India to Brazil, because they infringed European intellectual property, and were deemed counterfeit (Bate & Attaran, 2010).

The counterfeited goods industry has grown immeasurably in recent years due to globalisation and changes in consumer preferences (Wall and Large, 2010). The Web enables thriving criminal business to capitalise further on this aspect (Satchwell, 2004). There have been calls for global standards to authenticate medicines with tracking and tracing technology or by creating standards for medicine sales online (Attaran et al., 2012). This could be similar to the Framework Convention on Tobacco Control (FCTC), which implemented a protocol to eliminate illicit trade in tobacco products.<sup>19</sup> This protocol legally mandated global tracking and tracing for tobacco products and internationally criminalised illicit trade, which makes the law on fake cigarettes tougher than the law on fake medicine.

#### **1.4.2. Challenges to governance: criminal activity**

The Web allows people to view websites outside of their jurisdiction. It enables access to unregulated pharmacy sites that are not governed or authorised to sell medicine. Illicit online pharmacies have been described as a form of cybercrime that is the preeminent global governance challenge of the 21st century (Lewis, 2003). Illicit online pharmacies are seen to present a threat to global public health and to global cybersecurity (Mackey & Liang, 2011). Online medicine consumers are seen to be at risk from cybercrimes such as fraud or theft, funding organised crime and exposure to computer viruses by a

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<sup>17</sup> According to WHO: A generic drug is a pharmaceutical product, usually intended to be interchangeable with an innovator product, that is manufactured without a licence from the innovator company and marketed after the expiry date of the patent or other exclusive rights.

<sup>18</sup> Oxfam: Eye on the ball: medicine regulation- not IP enforcement- can best deliver quality medicines. 2011. <https://www.oxfam.org/sites/www.oxfam.org/files/eye-on-the-ball-medicine-regulation-020211-summ-en.pdf>

<sup>19</sup> [http://www.who.int/fctc/protocol/Protocol\\_summary\\_en.pdf?ua=1](http://www.who.int/fctc/protocol/Protocol_summary_en.pdf?ua=1)

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number of public health and law enforcement stakeholders, including WHO, the UN Office of Drugs and Crime (UNDOC), the International Criminal Police Organization (Interpol), the FDA, National Association of Boards of Pharmacy (NABP), the USA Federal Bureau of Investigation (FBI), the International Pharmaceutical Federation, The European Federation of Pharmaceutical Industries and Associations, the Pharmaceutical Research and Manufacturers of America, the Generic Pharmaceutical Association, and the Pharmaceutical Security Institute. The criminal actors (the illegal manufacturers, organized crime, illicit online pharmacies), non-criminal actors (often the consumers), and others that enable the operations (including Internet Service Providers (ISPs), search engines, social media platforms, payment processors, etc.) create a contentious grouping who make it difficult to regulate or control online pharmacies at the domestic level (Mackay & Liang, 2011).

### **1.4.3. Challenges to expertise: health implications**

Individuals can use the Web to make their own healthcare choices without the need to visit a doctor. Purchasing medicine without reference to a healthcare professional is seen as making people vulnerable to a variety of health risks, including addiction and misuse of medicines, adverse effects, and in the most extreme cases the risk of death. In addition to offering a route for purchasing medicines the Web allows individuals to expand their knowledge about health and medicines using information online and this may further loosen the grip of healthcare professionals and increase patient autonomy (George, 2006). Thus the Web challenges the traditional model of healthcare where clinicians and healthcare professionals control knowledge and expertise and constrain choice for the patient (Childress, 1982). There has been much discussion within academic literature about consumerism and the ways this has challenged the expertise of the medical profession – indeed Lupton (2003, 1997) and Hardey (2001) suggest that individuals are consumers rather than patients when they go online.

Using the Web to obtain medicines may be perceived as a risk, as people do not have the same expertise as healthcare professionals to ensure that they are

taking the correct treatment. Self-medication<sup>20</sup> using over-the-counter (OTC) medicines has been a longstanding feature of healthcare (Blenkinsopp and Bradley, 1996) but the Web opens up access to a far wider number of medicines including those previously only available via prescription. Lupton (2003) claims that the resulting 'fragmentation' of medical superiority, means that consumers are missing opportunities for advice and risk management.

The purchase of medicines online has been problematically framed as a risky for the consumer. Yet, this view of online medicine purchasing is underpinned by concerns about three challenges - to markets, governance, and expertise. The framing of risk - around individual patient behaviour - makes it possible to label patient/consumer behaviour as deviant. The criminological literature has explored how people respond to such labelling and so provides a helpful theoretical foundation for my thesis research.

### **1.5. Online medicine purchasing as a potentially deviant behaviour**

Web spaces provide an opportunity to purchase medicine, and circumnavigate the controls surrounding medicine regulation. In this respect it might be considered a deviant activity.

Our understanding of how activities are viewed as criminal and/or deviant is informed by labelling theory. Becker (1963) claimed that deviance is rule-breaking behaviour that is labelled deviant by powerful persons or groups. These ideas have been used to examine subcultures and societal reactions to rule breaking (Taylor, Walton and Young, 1973). From the earlier discussion it seems that online medicine purchasing sometimes breaks rules and transgresses regulation. However, these ideas about deviance have not been systematically applied to the examination of online medicine purchasing. Given

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<sup>20</sup> The Oxford English Dictionary's definitions of self-medication are to "*administer medication to oneself without medical supervision*" and to "*drink or take drugs to relieve stress or other conditions*". However, WHO has outlined how to self-medicate responsibly in accordance with assistance from a healthcare professional such as a pharmacist.<sup>20</sup> This suggests a different definition of self-medication, one where the patient collaborates with a clinician in order to establish a safe way of self-caring. However, the only medicines that are actively promoted for self-medication by the healthcare industry are those that can be obtained without prescription and are considered less of a risk due to their pharmacological compounds.

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the uncertain regulatory position of medicines purchased online, and these debates about risk it seems worthwhile to investigate whether or not consumers of medicines hold the view that online medicine purchasing is socially acceptable and whether others might perceive the behaviour as deviant. This thesis draws together ideas on presentation and deviance theories to form the concept of respectable deviance, in order to understand subjective accounts of online medicine purchasing.

### **1.6. Respectable Deviance**

Respectable deviance is the conceptual framework underpinning my analysis of the data on online medicine purchasing. It outlines how deviance is constructed, justified and managed. This thesis will present the argument that some online medicine purchasing involving prescription or controlled medicines, encourages particular presentations of self (Goffman, 1959) and techniques of neutralization (Sykes and Matza, 1957) such that it can be understood as a form of respectable deviance. My claims are not an attempt to integrate theories; rather, I draw on these conceptual tools to inform my analyses and the development of online respectable deviance. Therefore, I have not attempted to create a total theoretical framework, however, by bringing together these ideas to address the issue of online medicine purchasing, I offer a novel contribution to the field.

### **1.7. Research Questions**

This research sets out to explore online medicine purchasing via a mixed method approach to this contemporary phenomenon. It was initially driven by the research question: ‘how and why do people purchase medicine online?’ However, this was too broad and needed to be focussed to make the research manageable within the doctoral programme of study. Drawing and building upon existing research (which will be discussed in Chapters two and three), the following questions were developed to provide focus the research.

1. What are the routes for online medicine purchasing?
2. What types of medicines are available for sale online and what types of websites sell these medicines?

3. Who is purchasing medicine online?
4. What drives online medicine purchasing and how can we better understand the practice?
5. How do people engaged in online medicine purchasing view their conduct once aware of it being constructed as risky and problematic by external agents?

In order to answer these questions the following objectives were set:

1. Describe the different routes for online medicine purchasing (Exploring the range of illegitimate and legitimate means of procuring medicine online).
2. Identify the types of medicines available online, and the types of websites that sell these medicines (Extending the existing literature and mapping the availability of medicines online).
3. Obtain demographic information about who is purchasing medicine online
4. Examine people's accounts of purchasing and not purchasing medicine online (Obtaining novel insights into online health behaviours).
5. Apply a theoretical framework to explain how people manage purchasing illicit medicine online and engaging in behaviour that is constructed as risky by external agents (Exploring online deviancy and informing policy).

### **1.8. Aim and scope of the thesis**

The aim of this thesis is to examine and understand the purchase of medicines online and to explore consumer/patient behaviour and attitudes surrounding the purchase of medicine from the Web. While the Web is a global phenomenon, the main focus of my research is the UK. However, some of the literature referred to in this thesis originates in different countries, and some of the data are not limited to the UK, as the geographical locations of

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participants in Web forums, online surveys and non-face-to-face interviews cannot be verified<sup>21</sup>.

Web Science recognises the importance of utilising an interdisciplinary approach to the study of the Web and encourages the application of different disciplinary methods, theories and frameworks to advance our understanding about online and offline worlds. From the perspective of this research, Web Science has enabled an exploration of online behaviour, new insights into offline behaviour, and the social impact of the Web.

### **1.9. Summary**

Contextualising the purchasing of medicine online has theoretical, methodological and practical significance. This thesis has implications for the application of theories of deviance to the Web. I argue that the Web enables individuals to challenge healthcare expertise, and creates opportunities for people to bypass traditional healthcare channels and engage in behaviour that can be perceived as risky. Online medicine consumers are aware that they might be perceived as deviant, and so provide justifications, and/or manage their presentations to support illegitimate actions and appear respectable. In this thesis I will show how using mixed methods uncovered contrasting presentations and how the concept of respectable deviance can be used to understand online medicine purchasing.

Online research is continuing to grow in popularity, especially within the social sciences (Lee, Fielding and Grant, 2008). Online research methods have been embraced by drug studies in particular, due to their ability to provide relative anonymity and expanded access to otherwise difficult to reach populations (Van Hout & Bingham, 2013a; Sumnall et al., 2011; Winstock et al., 2011; Barratt & Lenton, 2010). Within this field, online surveys, online recruitment of participants, and unobtrusive monitoring of websites and forums have been primarily adopted (see reviews by Barrat & Lenton, 2010; Miller and Sonderlund, 2010). These approaches have been principally used to

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<sup>21</sup> Even in Skype interviews the location can easily be falsified. It is possible to put your location as anywhere in the world. For online surveys the ISP could be checked but this would breach confidentiality.

investigate the issue of online medicine sales and purchasing (Sugiura et al., 2012; Harte & Meston, 2011; Schnetzler et al., 2010, Baker et al., 2003). In this thesis I draw on these methods but also implement innovative online methods from the wider web research field, including the use of synchronous and asynchronous online interviews, online survey, social media, and online discussion groups as a method of recruitment and engagement with potential participants. I supplemented these mixed online methods with traditional offline methods such as face to face and telephone interviewing. I also wrestled with the ethics of doing online research, and so consider of the challenges in determining whether online spaces are private or public.

Previous studies look at numbers of online pharmacy websites and their attributes (Orizio et al., 2011) but little is known about the demographics of online medicine consumers and how they are making the transactions. There have also been studies of the motivations for online medicine purchasing (Liang and Mackey, 2009; Banks et al., 2009; Levaggi et al. 2009; George, 2006; Makinen et al., 2005; Shabsigh et al., 2004; Bellman et al., 1999). In this thesis, I explore who buys online and their reasons for purchasing, to see how of the categories of patients and consumers intersect, and how people construct and respond to risk. My findings have implications for regulation and safety surrounding medicines online.

### **1.10. Outline of Chapters**

This chapter has provided the aim of this study, which is to investigate online medicine purchasing. It has also presented some of the background to the research. Chapter Two will look in more detail at how medicines came to be available to purchase online and the new opportunities this creates. The role of the Web in consumerism and online healthcare debates will be explained to understand how purchasing choices are made and some of the associated 'problems'. How people use the Web to find health information will be considered in relation to how people are finding out about online medicine purchasing. The chapter then discusses how medicine has been illegitimately obtained prior to the Web, to demonstrate that such behaviours existed 'offline', before exploring the distinctions between legitimate and illegitimate online medicine purchasing. The chapter will then look at the size and scale of

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online medicine purchasing, and previous research on the demographics of purchasers. The chapter concludes with a consideration of motivations for online medicine purchasing.

Chapter Three will look in more detail at the risks involved with online medicine purchasing and review recent policies in this area. Using literature on deviancy, it will consider how people have responded to being labelled deviant, and the theories that have previously been used to explain transgressive online behaviour. The literature reviewed in this chapter provides the foundation for the concept of respectable deviance.

Chapter Four will present an overview of the methodology employed and justify the choice of methods used. It will situate my work in relation to contemporary online ethnography and describe my sequential, three-stage mixed methods study design. The chapter will also discuss some ethical considerations in researching the online environment.

Chapter Five is the first empirical chapter. It describes the opportunities involved in online medicine purchasing. I will show how consumerism is a key theme in online medicine purchasing. The chapter will outline the routes to purchasing medicine online, the types of medicine that are available to buy online, and what types of websites sell medicines. It also investigates who is purchasing medicine online.

Chapter Six is also an empirical chapter, which will address the risks associated with online medicine purchasing. It will highlight how availability and need are key themes involved in driving online medicine purchasing. The chapter considers how disputing the hegemonic norms of medical expertise and governance with justifications, challenges the 'risky' discourse associated with online medicine purchasing.

Chapter Seven addresses the concept of respectable deviance in relation to online medicine purchasing. It will outline how deviance is constructed; in this case those purchasing medicine online are aware that it is viewed as a risky behaviour, and highlight how deviance is responded to. Here Erving Goffman's work on performance and the presentation of self will be combined with Sykes and Matza's 'techniques of neutralization' in order to understand how some people justify and manage their online medicine purchasing.



Chapter Eight will draw together the arguments of the previous chapters and demonstrate how the concept of respectable deviance can be used to understand how people manage their presentations when discussing online medicine purchasing behaviour. I will show how I have contributed to the emerging body of knowledge about online deviancy, and to online research methods and research ethics for Web Science.

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## **2. Medicine and the Web**

An initial literature review was undertaken in order to inform my study design, discover the key research that has been undertaken in this area, and identify gaps in existing knowledge about online medicine purchasing. The purpose of this chapter is to explore medicine and the Web; in particular how people get medicines online and to demonstrate how research questions one to four emerged. I begin this chapter by providing background context to online medicine purchasing, with a discussion about consumerism in order to understand how people choose to purchase from the Web. This shows how the Web is a space for purchasing items, which includes medicines. The chapter then turns to online healthcare debates and some of the challenges involved with online healthcare and consumerism. Having addressed the legal routes to procuring medicine in the previous chapter, I then consider how unauthorised medicines have been obtained offline. The chapter will also discuss the blurred distinctions between legitimate and illegitimate online medicine purchasing. I then turn to the availability of medicines to buy online and the types of websites selling medicine online.

The chapter will show that current academic work provides limited knowledge about online medicine purchasing, and has not afforded a voice to the online medicine consumer. The chapter begins with the wider debates about consumerism and the Web, providing contextual background for this thesis research.

### **2.1. Consumerism and the Web**

The Web has become a place to buy and sell products and services. This involves providing and advertising information about goods as well as the purchase interaction. Goldsmith and Bridges (2000) describe web consumerism as information obtained from advertising, shopping that encompasses both browsing and specific information searches, and the purchase of goods, services and information. E-commerce is a fast growing retail market and online sales in the UK, Germany, France, The Netherlands, Sweden, Italy, Poland and Spain grew from £132.05 bn [€156.28 bn] in 2014 to £156.67 bn

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[€185.39 bn] in 2015 (+18.6%) (Centre for Retail Research, 2015). Online sales are expected to grow again to reach £182.80 bn [€216.32 bn] in 2016 (+16.7%) and £215.38 bn [€250.28 bn] in 2017 (Centre for Retail Research, 2015) and this will inevitably impact on offline sales.

The growth of online shopping has been the subject of much academic research, with many studies focusing on consumer's motivations. However, opinion has been divided as to whether online shoppers are fundamentally different from regular offline shoppers.

Earlier research claims that online shoppers require more product information, product variety, and more personalised or specialist products than their offline counterparts (Burke, 1997; Syzmanski & Hise, 2000). They are considered to be more concerned with convenience (Chiang & Dholakai, 2003; Donthu & Garcia, 1999), will pay extra in order to save time (Burke, 1997; Li et al. 1999; Morganosky and Cude, 2000; Syzmanski & Hise, 2000), and are generally averse to regular shopping (Burke, 1997; Morganosky and Cude, 2000). Levy et al. (2005) contend that that online shoppers are distinct from regular shoppers, based on their application of the Big Middle Theory. They define the Big Middle as "*the market space in which the largest retailers compete in the long run, because this is where the largest number of potential customers reside*" (Levy et al. 2005:85) and suggest that it is the creation of a unique type of shopper – the online consumer- that has necessitated retailers to move to the Web. These online consumers demand a specific type of service involving product variety and consistent low prices (Ganesh et al. 2010). Other significant factors that discriminate between online and offline shopping involve heightened perceptions of risk (Forsythe & Shi, 2003; Garbarino & Strahilevitz, 2004; Lee & Tan, 2003) and the ability to search for information and products (Chiang & Dholakai, 2003).

It has also been claimed that online shoppers are distinct from offline shoppers because they are not motivated to shop for fun or recreational purposes (Li et al. 1999; Mathwick et al. 2001), however, this was challenged by Wolfinbarger & Gilly (2001) who argue that as they do offline, consumers shop online for both goal-oriented and experiential reasons. Wolfbarger and Gilly (2001) identified various attributes that facilitate goal-oriented online shopping, including accessibility/convenience, selection and information availability.

Importantly, they found that consumers report that shopping online results in a substantially increased sense of freedom and control as compared to offline shopping. Nevertheless, while consumers are more likely to describe offline rather than online shopping in experiential terms, there is emerging evidence of experiential motivations for online shopping.

Although the earlier studies claimed that online shoppers are distinct, a more recent study presents a compelling case that the majority of online shoppers are in fact more similar to offline shoppers than they are different. Ganesh et al. (2010) argue the core motivations that influence purchasing are the same, irrespective of whether the item being purchased is on or offline. The key factors of choice and convenience continue to drive consumer behaviour. O'Brien (2010) in her study on utilitarian motivations in online shopping, also found that efficiency and cost are salient considerations for engagement within both physical and online shopping environments.

Ahuja et al. (2003) also noted that the motivations for online shopping include convenience, selection, price, original services, personal attention, easy and abundant information access, and privacy. This study which surveyed two samples (students and non-students) to gather quantitative data, focused on individual online purchasing behaviour. The authors also found that security and privacy concerns were the single biggest barriers to online shopping and was more important than price. In Ahuja et al's study the purchase of healthcare items was less popular (Ahuja et al. 2003). Nevertheless, although the numbers of both students and non-students buying health products at that time were not hugely significant, many were intending to become online healthcare consumers in the future.

One important aspect of online purchasing is trust. In 2002 The Consumer Web Watch reported that there was a 'lack of trust' in Ecommerce, nonetheless studies have shown increasing popularity of the Web as a purchasing tool (Cofta, 2006). Mackey & Liang (2011) claim that online medicine vendors may disguise the risks of their products and this is a theme to which I return in Chapter Three. The next section will explore trust and how consumers make decisions on the Web.

### **2.1.1. Consumer trust in the Web**

Trust is a crucial aspect of the consumer-market relationship (Dwyer, Scurr and Oh, 1987). According to Riegelsberger, Sasse & McCarthy (2005) the basic model of trust is only needed in circumstances characterised by risk and uncertainty. Risk and uncertainty arise from a lack of information regarding the other actor's abilities and reasoning (Deutsch, 1958). In eCommerce positive customer views on websites can be seen as symptomatic of reliability and good service, demonstrating how the Web facilitates the formation of trust.

Riegelsberger, Sasse & McCarthy (2005) describe how online vendors indicate that they are looking to not only attract potential customers but to ensure that business is continued with them afterwards. The appearance of websites as professional has also been acknowledged as a key indicator of trustworthiness (Egger, 2001; Fogg, 2003; Nielsen et al., 2001; Riegelsberger et al., 2001; Schneiderman, 2000).

Riegelsberger et al. (2001) found that reputation is a major consideration when deciding whether or not to purchase online. In their interviews, participants stated that they responded to their friends' and families' recommendations and experiences with online sellers (Riegelsberger et al., 2001). In addition, media coverage or consumer reports were also influential. It should be noted that this study claimed that from a consumer perspective, reputation was not treated as an incentive for trustworthiness, rather as information about the competence or integrity of the vendor. However, acquiring or maintaining a positive reputation provides impetus to the vendor to act trustworthily (ibid).

Offline signifiers have also been identified by researchers as influential on trust (Egger, 2001; Schneiderman, 2000; Riegelsberger et al., 2001), for example 'real-world' addresses and/ or contact telephone numbers, suggesting that the Web amalgamated into everyday life is important to consumers. Riegelsberger, Sasse & McCarthy (2005) point out offline locations can highlight that the vendor is in a jurisdiction with different regulations (e.g. consumer protection laws). This can be interpreted as an indicator of trust or a reason to distrust depending on the situation.

Drivers and the role of online trust differ between different websites and consumers. Bart et al. (2005) claim that trust drivers and behavioural intent differ significantly between consumer groups and different websites and the

products they sell. For websites that involve high information risk and involvement such as travel sites, privacy and order fulfilment are the most influential determinants of trust (ibid). For information intensive sites such as sports or community sites, navigation is highly significant. For categories of websites that incur high involvement like automobile and financial service sites, brand strength is imperative, whilst advice is critical in the search for categories with high financial stakes such as expensive electrical items (ibid). Online trust partially conciliates the relationship between website, consumer characteristics and behavioural intent and it is for costly, infrequent purchases that this conciliation is strongest. Conversely it is weakest for sites that elicit frequent use. The suggestion is that the influence of different drivers on online trust is generally the same for most consumers; however, there is a marked distinction for consumers for whom brand strength and advice are the most important determinants of online trust. People with higher levels of education are more influenced by brand names more than people with lower levels of education (ibid). Though the authors do not expand on whether there is a correlation with income and education for their participants, which may have a socio-economic impact on purchase decision-making.

Turning to consumer's trust of online pharmacies a study by Banks et al. (2009) has produced some useful indicators regarding the risks associated with purchasing medicine online without prescription. The study found that most respondents, when asked to rate the risk of certain behaviours on a 7-point scale (1 = not at all risky; 7 = very risky), rated taking prescription medicine without a prescription as very risky. However, many of the participants were unaware of the correct classification of common medications. The aesthetics of the website were important as respondents said that when purchasing prescription only medicine without a prescription they would use a search engine and select the most professional-looking site. However, 74% reported that the possibility of medicine being counterfeit would have a severely negative impact on their likelihood of purchasing without a prescription (ibid).

It is interesting to note that health-related risks (quality of the medicine and prescription requirement) appear to rank lower in consumers' perception than security issues. Gurau's interviewees reported being worried by lack of a licence on the part of the pharmacy (31%), privacy issues (27%), security of

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online payment (26%), additional charges, drug quality and superficial prescription (Gurau, 2005). In Fox's (2004) survey, meanwhile, 68% agreed that online purchasing makes it too easy to obtain drugs illegally.

In a study investigating consumer's trust in online prescription medicine information it was held that the trust in medicine information from traditional media sources such as television and newspapers extends to the Web (Menon et al., 2008). The same study also found that there is a greater trust in online prescription medicine information after the consumer has been exposed to advertising. However, Menon et al. (2008) determined that there were no significant socio-demographic differences related to trust of prescription medicine information online. This finding is contrary to previous studies that found socio-demographic distinctions in access, use and trust of health information on the Web (Brodie et al., 2000). Instead self-reported health status was significant, with consumers who presented a positive self-health status more inclined to trust online health information, whilst consumers who were more unwell preferred to depend on information administered by a healthcare professional. However, there are limitations to this study, with secondary historic survey data used, which did not allow for respondents level of web access and the possibility of biased measurement.

Fittler et al. (2013) surveyed patients regarding online medicine purchasing and found that patients are not fully aware of the risks of potential dangers associated with purchasing medicine online. The implication is that patients are unable to differentiate between legal and illegal online pharmacies. However, this is only a presumption as the survey did not directly ask respondents to make this distinction; also the survey was administered to Hungarian hospital patients and so the findings are not generalisable to the wider online medicine purchasing community.

This investigation on trust has highlighted how it has been recognised within academic literature as an important factor in online purchasing and decision-making. Previous studies have suggested that trust has been used to mitigate potential risks.

The challenges and risks associated with online medicine purchasing become more prevalent when the action is illegitimate or illegal. The illegal pharmaceutical trade is more likely to be dealing in counterfeit medicines, and



acting outside of governance, being involved in or supporting criminal activity, and operating outside of healthcare expertise and risking safety, are all heightened when illegitimate or illegal sites are involved.

## **2.2. The challenges of online healthcare consumerism**

The development of eHealth has revolutionised the delivery of contemporary healthcare. Mackey and Liang (2013) describe Ehealth as a multidisciplinary intersection of medical informatics, referring to health services and information that is delivered via the Internet and related technologies. Likewise the term 'Medicine 2.0' has been used to describe consumer use of interactive social networks and health related applications (Eysenbach, 2008). The benefits of eHealth technologies include their potential to improve health education, outreach, disease surveillance, collaboration, communication between patients and healthcare providers, and support of decision making (Black et al., 2011; Blaya et al., 2010; Eysenbach, 2008; Fjeldsoe et al., 2009; Lewis et al., 2012; Piette et al., 2012). The outcome of such benefits can impact health provision at a distance, where access and delivery of healthcare in low-income and rural settings, for example; along with reduced healthcare costs and better health outcomes from technological investment (Black et al., 2011; Blaya et al., 2010; Eysenbach, 2008; Fjeldsoe et al., 2009; Lewis et al., 2012; Piette et al., 2012). As a result the adoption of eHealth technologies are exponentially increasing (Black et. al, 2011; Mair et. al, 2012; Piette et. al, 2012).

Amongst the eHealth transformation are sites that trade legally and legitimate online pharmacy retailers, which have transformed traditional global and domestic marketplaces in positive ways. The number of online pharmacies has increased, as it has been recognised that the Web can serve as an important source of health-related products, services and treatments (Larkin, 2004). This has increased access and choice and the ability to negotiate treatments (Hardey, 2001; Lupton, 2003; Nettleton, 2004), for example providing greater access to medicine for the housebound or disabled and those living in remote areas, ensuring more anonymity and making medicines more affordable (Bruckel and Capozzoli, 2004; Fung et al., 2004; Henney, 2001).

### **2.2.1. Expertise**

Online pharmacies may transform the relationship between patients and professionals (Fox et al. 2005). Within healthcare, an emphasis on the 'patient' or 'user' as 'consumer' with the implied ability to make decisions based on information and experience has emerged (Hardey, 2001). Lupton (1997) conducted research focusing on changes in lay people's attitudes towards the medical profession in response to increasing consumerism. Lupton (1997) noted that the established notions of consumerism that tend to assume that lay people act as rational actors in the context of the medical encounter align with broader sociological concepts of the 'reflexive self' as a product of late modernity. In line with notions of the reflexive self of late modernity and Giddens (1990) 'reflexive' consumer, this suggests the self who acts in a calculated manner to engage in self-improvement and who is skeptical about expert knowledge. However, Lupton's (1997) study involving 60 in-depth interviews with lay people; found that in interactions with health care professionals, lay people may present themselves as both the consumerist and the passive patient. She argues that patients have agency too and do not always act 'rationally' within the context of the medical encounter (Lupton, 1997).

Fox et al. (2005) considered the role of the 'informed consumer' in their study of online weight loss forums. Their findings evidenced how participants share information and support each other as they use slimming treatments and, in doing so, become 'expert patients' in relation to their body shape and its management. The study also questioned whether knowledgeable patients who, as consumers, make learned healthcare choices might challenge dominant discourses in healthcare.

Informed patients/consumers may engage with health information and technologies freed from the constraints of professional control and governance. Informed patients can resist medical expertise and use new media and virtual communities (Rheingold, 1993) to develop expertise that empowers (Hardey, 1999). Burrows et al. (2000) also explored the use of the Web for online self-help and support, in a term referred to by the authors as 'virtual community care.' Similar to Hardey, Burrows et al. highlight the privilege of lay knowledge and experience over the expertise of health care professionals,

evident within online self-help groups. Furthermore the nature of the patient-doctor relationship, the quality and legitimacy of advice, information and support, and the potential for empowerment or social exclusion, is explored. They contend that regardless of whether or not people who engage in online self-help and support may constitute themselves into virtual communities, such individuals are using various types of computer - mediated communication to obtain and disseminate information, advice and support across a multitude of health and social issues (Burrows et al., 2000:101). Hardey claimed that the Web *“forms the site of a new struggle over expertise in health that will transform the relationship between health professionals and their clients”* (1999: 820).

Consumers are able to access a wealth of medical information online that allows them to have a better understanding of issues related to health and treatment. This may enable them to challenge the paternalism of healthcare professionals and boost patient autonomy (George, 2006). However, Hardey's later work (2001) claims that the Web is not necessarily clearly divided into the orthodox and non-orthodox camps of medical information. In his study, producers of health resources demonstrated that they included both approaches within the same webpages. In addition Hardy (2001) suggested that people use a range of different resources to comprehend illnesses and to shape their health. Although the doctor-patient relationship has been reconfigured with the emergence of the Web and consumerism people still want certain aspects of the traditional relationship, such as the development of trust through interaction, diagnosis and treatment (Hardey, 2001).

### **2.2.2. Health information online**

Many consumers use the Web to find information about their medicines and this allows them to challenge healthcare professionals (Menon et al.2008). Web 2.0 tools in particular, have had a significant impact on access to health information, so much so that it is not just lay people who access health websites, but doctors too (Giustini, 2006). Such information is presented in accredited websites as well as less formal blogs and social media sites. Health information online is of variable quality (Eysenbach et al., 2002) and therefore the search and appraisal skills of consumers are important for selecting and assessing this information. Although consumers may be able to verify

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information from offline sources via knowledge or experience, online information may not allow such validation (Caruso, 1997). The way consumers choose and evaluate information on medicines on the Web is important because it has been shown that written information on medicines can influence consumer attitudes to and use of medicines (Peterson et al., 2003). The study found that all participants reported searching the Web to find information on medicines and was informed by factors such as the workplace or educational environments, or suggestions by family or friends. Some participants found information solely by typing the medicine name (drug or brand name), while others searched using broader terms. Search skills ranged widely from more-advanced (using quotation marks and phrases) to less-than-optimal (such as typing in questions and full sentences). Many participants selected information from the first page of search results by looking for keywords and descriptions in the search results, and by looking for the source of the information within the URL. Opinions on credible sources of information on medicines varied with some participants regarding information by pharmaceutical companies as the 'official' information on a medicine, and others preferring what they considered to be impartial sources such as governments, organisations, and educational institutions. It was clear that although most participants were sceptical of trusting information on the Web, they had not paid conscious attention to how they selected information on medicines. Despite this, it was evident that participants viewed the Web as an important source for information on medicines (Peterson et al 2003).

Eysenbach (2001) also identifies concern with the information needs of patients, and attributes a specific role to interactive technologies such as the Web and claims there is a shift of emphasis towards consumers' information needs. However, Eysenbach is careful not to reify the Web or see it as the most appropriate means to deliver health information in all circumstances. For example, he argues that consumer health information is not restricted to the use of computers and telecommunications but also includes the delivery of information to patients through other media. Despite this he views the Web with a tendency for increased consumer control and self-reliance and makes the normative assumption, that people want to operate as healthcare 'consumers', to take more responsibility for their own health through 'self-care'.

Lapidus and Dryankova-Bond (2014) highlight the significance of directing web users to select the most accurate and reliable websites, emphasising those created by government, medical and commercial medical organisations. The paper is situated in the US and hence focuses on US based websites including: WebMD, Mayo Clinic, and the FDA Protecting Yourself page. As well as providing advice on side effects, ingredients, and contraindications, such websites also offer recommendations on purchasing medicine online; however, there is no discussion about how to effectively direct patients and consumers to these websites. Eysenbach (2009) has also noted that people may engage in a range of online activities which can impact on health. These might include searching for health information for others, using online behaviour change or disease management programmes and (in the US or private healthcare context) locating a suitable healthcare provider or health insurance. However, there is conflicting information about people's motives for seeking healthcare knowledge online.

People accessing online health information could use that intelligence for nefarious purposes, however, in some instances people are simply seeking information to inform and protect themselves. A collaborative study (Lee et al. 2014) involving clinicians at Guy's and St Thomas' NHS Foundation Trust and King's Health Partners, and Kings College London, found that the Web is used as a source of information about the harms of recreational drugs. This study challenges former research Deluca et al., (2012); Gordon et al. (2006); Walsh, (2011), which claimed that the Web is more likely to be used to access information on the synthesis, consumption and purchase of drugs.

Henwood et al (2003) following the work of Lupton (1997) argue that some of the assumptions regarding individuals moving towards self-care can be challenged. They also query whether there is a direct link between information access and empowerment, and if Web access and patient empowerment are inextricably linked. The authors challenge the notion that individuals want to take responsibility or seek out information for themselves, preferring instead to trust their doctors and leave healthcare decisions to them. The rights that come with consumerist healthcare are aligned with responsibilities, and the proposition is that the increased consumer/ patient responsibility for health is an unconvincing argument to the individuals concerned. People seem reluctant to assume total responsibility for their own healthcare management, and

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require some intervention involving medical expertise. In addition, Henwood et al. (2003) further contest the identity of the informed consumer, in particular the assumed competency of information literacy. Such competency would be expected to involve awareness of how and where to obtain information, information retrieval, understanding the context of the information provided, along with interpretation and explanation of the information in the wider background of health-care decision making. The authors found that although almost half of their study sample had used the Web to access health information, their search strategies were not rigorous or systematic. Substantiating Eysenbach and Köhler (2002) in their qualitative study of online health information searching, Henwood et al. (2003) also discovered that individuals had almost no awareness of who or what organisation was publishing the information they were accessing. In some cases the information media and source were depleted and the Web itself, was viewed as a valid source of health information.

Henwood et al. (2003) also claim that healthcare practitioners are hesitant to acknowledge the role of the informed patient/ consumer. Their analysis uncovered cases of women who had obtained information about their specific health condition and requisite treatments, but when they took this information to their doctors their opinions were dismissed and downplayed. The indication is that where lay knowledge does not concur with medical knowledge there will be conflict when a degree of compliance with medical opinion is deemed appropriate. Such findings reflect those from Dixon-Woods (2001) and Massé et al. (2001), which suggest that there are limitations to the prospect of information for choice that appears to be the agenda within the informed patient/ consumer discourse. Therefore the move from the patient to the informed consumer will not be a simple transition due to existing structures that impose constraints upon both practitioner and patient communities and the spaces they occupy during the medical encounter.

Furthermore, there is the argument that consumers are unable to make an informed decision about purchasing medicine online, using only information obtained from online pharmacy sites because proportional information about the benefits and risks is not available or of inadequate quality (Bessell et al., 2003). The health information published on online pharmacy web pages is insufficient or deficient (ibid).

Studies have suggested demographics and figures for those who access health information on the Web. The Oxford Internet Survey reported that in the UK, women were more predisposed to looking for health information online than men, while the unemployed and retired sought more online health information than students. Fox (2007), referring to the 2006 Online Health Search, a US survey by the Pew Internet & American Life Project, highlighted that “*prescription or over-the-counter drugs*” was the fifth most widely-searched health topic on the Web. The most recent study conducted by the Pew Project, in September 2012,<sup>22</sup> found that 72% of Internet users claim to have looked online for health information within the past year. This research is primarily concerned with US citizens and as such may not be applicable to UK users, but it gives an indication of the depth of interest. In the UK, a report by the Department of Health (2011) suggested a surge in UK users seeking information from the NHS Choices website.<sup>23</sup> This was linked with the flu virus that was suffered by many UK citizens during the winter of 2010. With this wealth of information, consumers may be in a better position to judge and understand health, illness and the body. These reports indicate that there is increased interest in health information online, where people are seeking to increase their medical knowledge and manage illnesses.

The literature has highlighted that the Web is a tool for healthcare consumers. It provides a new means to obtain medicines, one that potentially enables greater opportunities to challenge medical hegemony. This could be influential in online medicine purchasing, and this will be something I explore further in the empirical chapters of this thesis.

Procuring medicine outside of legal channels threatens medical dominance. The chapter now turns to how medicine has been illegitimately obtained ‘offline,’ before I consider the growth of the online pharmaceutical market.

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<sup>22</sup> <http://www.pewinternet.org/fact-sheets/health-fact-sheet/>

<sup>23</sup> <http://www.bbc.co.uk/news/uk-16370867>

## **2.3. Obtaining unauthorised medicine**

In the previous chapter I briefly outlined the UK legislative framework that determines how medicine can be legitimately purchased. In this section I will discuss the ways in which medicines and pharmaceuticals have been obtained outside these regulatory controls.

Before the advent of online pharmacies, the purchase of medicine in the UK was via pharmacies or regulated clinical practitioners. Obtaining medicine outside of these settings usually meant engaging in criminal behaviour associated with illegal drug use, drug dealing and the so-called black market. Wilson's (2007) ethnographic study into the 1970s Northern Soul scene showed how individuals who used illegal substances often engaged in criminal activities, such as the burglary of pharmacies, to obtain drugs and medicine. Other means of illicitly procuring prescription medicines include the forging or altering of prescriptions, impersonating a medical professional, or stealing blank prescription forms (Jamieson, Glanz and MacGregor, 1984). All of these acts fall clearly into the category of law breaking and were subject to prosecution and punishment.

In Italy there have been reports on the growing phenomenon of theft of medicines from hospitals. From 2006 – 2013 one hospital out of ten registered thefts of medicines, equating to a financial loss of about 330 thousand EUR in each instance (Riccardi et al. 2014). This has an impact on patients, pharmaceutical companies as well as the Italian national health system's economy. Riccardi's (2014) study suggested that cost and difficulty accessing medicines via legal channels were potential drivers for such thefts. The majority of medicines stolen are classified within the Italian national health economy, which may suggest that these products are being resold on the illegal markets of international countries.

Other ways of obtaining medicine without authorisation involve the borrowing and sharing of prescription medicine. Petersen et al. (2008) analysed US healthcare trends survey data from 2001-2006 and discovered that prescription medicine borrowing and sharing is a common behaviour among adults. The study claims that women rather than men are more likely to borrow or share medicine, such women are of reproductive age (18-44), and allergy



and pain medicines were the most common types of medicine borrowed or shared. This secondary data analysis offers some statistical information on the extent of medicines sharing but its generalisability may be limited to the US.

Drug misuse, where drug taking is deemed to be problematic, inappropriate or dangerous, is often viewed as distinct from legitimate medicine use. In some cases substances may be illegal, yet individuals seek to use them to treat illness. According to Robson (1998), many otherwise law-abiding individuals have procured illegal drugs to ease symptoms that are insufficiently controlled by conventional medicines. For example, cannabis has been recognised and trialled as an aid to ease the symptoms of arthritis (Blake et al., 2006) and multiple sclerosis (Rog et al., 2005). However, it is a Class C controlled drug under the UK Misuse of Drugs Act 1971, and is also illegal under the US Federal State Law, the Controlled Substances Act of 1970 (aside from in Colorado and Washington, where authorities have recently legalised the medical and non-medical (e.g. recreational) use of cannabis). Fraser and Moore (2011:11) suggest that the category of drugs is “*an entirely political one*” as it includes all the substances that society admonishes at any given time.

The reasons underlying the aforementioned illicit appropriations of medicines may fuel the demand for online medicine, thus increasing engagement in illegitimate online medicine purchasing. Although the inclination suggested within public perception has been that OTC medicines are safer than prescription medicines (Bissell et al., 2001; Hughes et al, 2002; Raynor et al., 2007), OTC medicines have been recognised as having the potential for harm as well as benefit (Lessenger &Feinberg, 2008). OTC medicine can be misused or abused<sup>24</sup>, with addiction and dependence purported as motivations (Mattoo et al., 1997; Orriols et al., 2009; Nielsen et al., 2010).

Obtaining unauthorised medicines occurred before the Web (and co-exists independently of it), but it is much easier to apply the law and recognise such behaviour as illegal. This is due to the nature of the Web itself as discussed in Chapter 1 (1.8). The unregulated spaces of the Web challenges national laws

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<sup>24</sup> The distinction between misuse and abuse is contentious. Fleming et al. (2004) contends that misuse is applied to potentially all medicines, whilst abuse is related to specific medicines that can cause more physical harm, such as laxatives, antihistamines and codeine-based products. Misuse can involve the consumption of larger quantities than the recommended dose, or using it to treat symptoms for which the medicine is not meant for (Abbot & Fraser, 1998).

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and allow possibilities for criminal and deviant activities (Yar, 2006). Further consideration of the unique nature of the Web in transforming other types of deviance will be undertaken in Chapter Three.

It is clear that unauthorised medicine purchasing is not confined to the Web. However, this thesis argues that the Web is increasingly a source for purchasing medicines, some of which are unauthorised.

### **2.4. Availability of Medicines online**

Online sales of medicine began towards the end of the 1990s (Gallagher and Colaizzi, 2000). Consumers wishing to obtain prescription medicine can visit a licensed prescriber for a prescription or purchase it from the Web using a 'cyberpharmacy' or online pharmacy (Orizio and Gelatti, 2010). In 2008, the online pharmaceutical market was estimated to be worth \$11 billion (MarkMonitor, 2009) and since then the demand has shown no signs of abating.

The Web has impacted on the pharmaceutical industry by enabling private sales to individuals (Wall, 2007). The Web traverses national borders and can enable global access to medicine. While previously people were unable to access medicines from abroad easily (unless they resorted to the illegal drug trade), the Web allows individuals to conduct such transactions from no further than the comfort of one's own home. Peer-to-peer networks can also host virtual negotiations about medicine in community spaces such as online forums and social media (Cordaro et al., 2011). The Web is an information resource, and health-related information has been reported as one of the main reasons individuals use the Web (Pew, 2012; Eysenbach, 2001). Sharing such information may encourage or facilitate buying medicine online, and direct marketing techniques based on users' search terms or browsing habits are used to encourage purchasing. Online medicine vendors may use targeted marketing to attract vulnerable patient groups, such as seniors, adolescents, the uninsured or underinsured, handicapped persons and people with low socio-economic status (Liang & Mackey, 2009).

The online purchasing of medicines presents new challenges to the regulatory frameworks described in the previous chapter. For example, if a medicine is withdrawn in one country, it may still be licensed or available in others (Montoya & Jano, 2007). Such medicines are often available for sale online to individuals where they are not licensed, from countries where they are licensed, which raises complicated questions about the legitimacy of the transaction. Furthermore, though regulations restrict the sale or provision of prescription medicine in the UK for example, individuals are able to evade the law by purchasing outside of these controls, online. Nevertheless, online medicine prescribing without prior doctor-patient interaction is still considered to be unethical or unlawful (Eysenbach, 2001).

## **2.5. Legal, legitimate, illegitimate and illegal medicine purchasing**

Online medicine purchasing has been framed as a risky behaviour, this will be discussed more in the next chapter, however, it is important to note that ‘risks’ are considered greater when the purchasing is illegitimate or illegal.

Nevertheless, distinguishing between legal, legitimate, illegitimate and illegal online medicine purchasing is complicated as current legislation is not clear about the role of the consumer, and the categories overlap with each other.

From a UK perspective legal online medicine purchasing is convoluted due to the fact that purchasing is not explicitly addressed within medicine regulation. Consumers have legal access to medicine via the same mechanisms as they do offline depending on the classification of medicines (as per the Medicines Act 1968<sup>25</sup>). General sales list medicines can be legally bought online without a prescription, from a registered pharmacy, whilst OTC medicines can also be legally bought online from registered pharmacies without prescription. However, with the latter a pharmacist should be consulted and health checks obtained before the transaction is complete. In order to legally purchase prescription only medicine online, the consumer must have a valid prescription obtained from a licensed health care professional, and use a registered online

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<sup>25</sup> <http://www.legislation.gov.uk/ukpga/1968/67/contents>

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pharmacy. There is an onus on the consumer to have engaged in a direct meeting with a healthcare professional beforehand, in order to procure a prescription. In all instances, for the consumer to be legally accessing medicine they need to be using a registered online pharmacy. Registered online pharmacies are either online versions of offline pharmacies with pre-existing valid pharmacy licenses, or online pharmacies that are registered with an accredited board such as the Royal Pharmaceutical Society (RPS) or the National Association of boards of Pharmacies (NABP), which has established the Verified Internet Pharmacy Practice Sites (VIPPS)<sup>26</sup> programme to assist consumers in making informed choices. Registered online pharmacies operate as they do offline, adhering to regulation, and possessing a licence to prescribe (Bostwick and Lineberry, 2007; Mills, 2000).

Legitimate online medicine purchasing shares some factors as legal online medicine purchasing, but consumers may be using websites that are not registered online pharmacies, nor have they visited a healthcare professional beforehand. However, transactions are legitimate because the consumer is not purchasing prescription only medicine and so are still adhering to legislation. Rather the action is not meeting the authorities expectations about how medicine should be obtained. Namely that professional advice should be obtained prior to procuring medicine and that the consumer should only be using pre-approved online retailers. The consumer is thus a potential problem (to the authorities), though this group is not presented as a significant social concern. Furthermore there are complications where international websites are used. Websites trading from their own jurisdictions may adhere to national laws, but these might differ from those of the country where the consumer is based. This is an area which crosses over into the illegitimate purchasing domain, however, the distinction lies with the type of medicine bought.

Even though they may be engaging in illegitimate online medicine purchasing the buyer is not prosecutable. However, they are purchasing medicine, which is not legally being sold, such as prescription medicine without a valid prescription (Weiss, 2006). In order to be able to procure such medicine unregistered pharmacies are used, and often these are international websites who are providing medicines consistent with their own domestic laws, but are

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<sup>26</sup> <http://www.nabp.net>

not licensed to sell to other countries. In purchasing prescription medicine online without a prescription, the consumer is engaging in behaviour that is unauthorised and challenges societal norms about acceptable health practices. Such behaviour moves beyond what is the 'respected' way to appropriate medicine and may be constructed as societally problematic, by the authorities and the media, who may influence the public in turn. Although in the UK the law only applies to the sale and supply of medicines<sup>27</sup>, it is an established custom that certain medicines require a prescription before they are dispensed. The sale of prescription medicine without a prescription violates regulations but the consumer might not be fully aware that they are purchasing items sold illegally (Lavorgna, 2015). Seeberg-Elverfeldt (2009) states that in order to protect consumers from illegal online medicine sales, they need to be able to easily identify the legal products for sale on the Web. Illegitimate online medicine purchasing also encompasses pharmaceuticals that fall into the grey area of regulation, such as novel psychoactive substances or 'legal highs' and research chemicals. These are neither currently not necessarily illegal but nor are they legal either,<sup>28</sup> and these have been associated with anonymous online markets, such as the infamous Silk Road. Distinct from unlicensed pharmacies, there are no pretenses of legitimacy or claims of being a pharmacy. These anonymous online marketplaces act as a middleman bringing together vendors of pharmaceutical goods with prospective customers. Consumers know they are purchasing illicit products from online 'black' markets and depending on the substances bought may be acting illegally.

It is only when purchasing illegal drugs (as defined by the Misuse of Drugs Act 1971<sup>29</sup> for example) that the consumer/purchaser becomes liable for prosecution for purchasing and possession. Illegal online medicine purchasing is intertwined with the illegal pharmaceutical trade and therefore, carries the same connotations as the traditional illegal drugs trade.

The discussion above demonstrates that these categories are on a continuum, however, whilst legal and illegal are understood as legislative distinctions and

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<sup>27</sup> [The Human Medicines Regulations 2012](#)

<sup>28</sup> There are plans afoot to implement the following bill:

<https://www.gov.uk/government/collections/psychoactive-substances-bill-2015>

<sup>29</sup> <http://www.legislation.gov.uk/ukpga/1971/38/contents>

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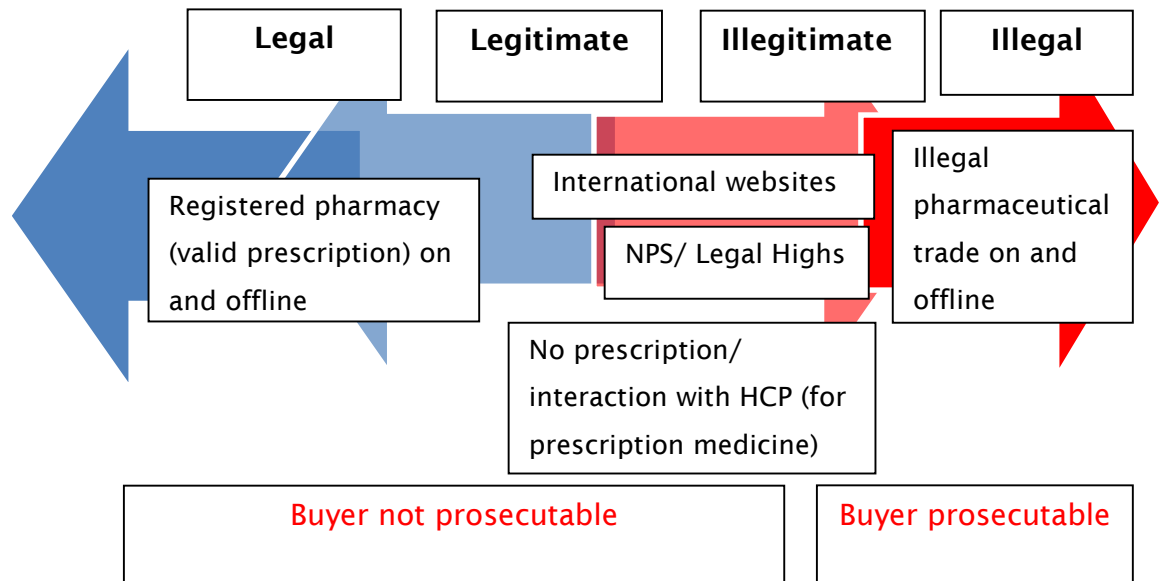
whether criminal law applies or not; legitimacy and illegitimacy are societal constructions. As a way of illustrating these issues regarding legality, legitimacy, illegitimacy and illegality in online medicine purchasing Table 1 summarises the sources for obtaining prescription medicines, Figure 1 then shows the legal through to illegal routes to obtaining medicine and indicates the blurring between these two distinctions.

Table 1 Sources of obtaining prescription medicine

	<u>Pharmacy Source</u>		<u>Non-Pharmacy Source</u>
<u>Legal</u>	A: Legally manufactured medicines available on prescription  (Registered online pharmacies)		
<u>Illegal</u>	B: medicines containing illegal substances not mentioned on the label and/or only allowed in the country in which it is produced	C: Legally manufactured medicine obtained without a prescription (i.e. pharmaceutical companies located in countries with fewer restrictions/unregulated websites)	D: Counterfeit medicines and/or those produced without a licence (i.e. underground labs fabricating their own substances/generic products)

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Figure 1 Legal through to illegal routes of online medicine purchasing



Although the literature considered so far provides some information about how people are purchasing medicine online, research has not considered how people come to make such purchases, in other words – what led them to the Web, and whether their routes to purchasing are from authorised channels. To unpack this further I reviewed studies about the types of medicine available to purchase online, which may give an indication about whether transactions are being conducted legitimately or not.

## 2.6. Types of medicine online

One factor that has fuelled the trend of purchasing medicine online is the growth and popularity of so-called ‘lifestyle medicines’ (Bostwick and Lineberry, 2007). These are pharmaceuticals that blur the boundaries between food products, cosmetics and medicines and include treatments for erectile dysfunction, weight loss, hair loss and stopping smoking. These lifestyle

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medicines also pose significant problems for the regulatory agencies (Jackson et al., 2012), and are widely advertised and sold online.

Medicines for weight loss, the flu, and for chronic pain were found to be those most commonly purchased online in the Fakeshare project (2015). There has also been an increase in the online sales of opioid analgesics and psychotropic substances such as stimulants, antidepressants and benzodiazepines (Forman, et al., 2006a; Raine et al., 2009). These substances are commonly misused, (Forman et al., 2006b; Forman et al., 2006c; Finley, 2009; Ghodse, 2010). WHO (2010b) also claims that the underground online market provides a wide range of pharmaceuticals from lifestyle to life saving medicines, which are extremely hard to distinguish from genuine products.

In addition, George (2006) claims that many online pharmacies sell nootropics, so called 'smart drugs' that claim to enhance cognitive abilities, whilst other sites promote growth hormones, and melatonin. In 2000 the Federal Trade Commission (FTC) in the US took action against several companies whose websites were fraudulently selling treatments for cancer and AIDS (FDA, 2000).

Substances that fall within the grey area of regulation, so-called 'legal highs,' have increasingly been offered for sale online (Schmidt et al. 2011, Davies et al. 2010, Hillebrand et al. 2010). Measham et al. (2010) claimed that the reduction in the availability of illegal drugs such as ecstasy and cocaine drove the online market for replacement novel psychoactive substances emulating the effects of the illegal drugs, which could be conveniently purchased legally.

These novel psychoactive substances have since been recognised as a major threat to public safety and recent legislation has been implemented,<sup>30</sup> which bans the generation of substances that induce a psychoactive effect, aside from societally acceptable products such as food, alcohol, cigarettes, certain medicines and caffeine. It remains to be seen what the impact on the online drugs markets will be and whether substances will be driven underground. Certainly studies have shown that classifying substances as illegal has led them to their greater availability for sale on the Web (Brandt et al. 2010). In a preliminary study to this thesis, accounts of online medicine purchasing were investigated, which included the resourcing and purchasing of slimming

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<sup>30</sup> <https://www.gov.uk/government/collections/psychoactive-substances-bill-2015>



treatments containing the specific ingredient of sibutramine, after it had been banned in Europe for its association with heart problems (Sugiura et al. 2012).

This discussion has shown there appears to have been an increase in the types of medicine available to purchase. The focus on lifestyle medicines as a primary issue for the regulatory authorities has been challenged by the emerging growth of other types of prescription medicine and substances that emulate illegal drugs. Building on the literature, my study aims to add to this body of knowledge and identify the current trends in types of medicine purchased online, and their types of classification. This will allow us to further investigate the legitimacy of online medicine purchasing.

Websites selling medicines pose a number of problems for regulatory agencies. The various forms of 'online pharmacies' can also help us to consider whether online medicine transactions are being conducted legitimately or not.

## **2.7. Types of websites selling medicine**

Bostwick and Lineberry (2007) distinguish four different types of web 'pharmacy'. The first is aligned with traditional physical pharmacy outlets, where prescriptions are filled out and received from doctors. These sites include high street stores such as Lloyds Pharmacy in the UK and CVS in the US.

The second type of online pharmacy is also legitimate and offers a range of products, including some medicines issued under prescription. Examples of such sites are Canadian pharmacies, for example Shoppers Drugs Mart. The third type is considered to be 'rogue' pharmacies, which require monitoring by agencies. These pharmacies use virtual prescribing via an online questionnaire reviewed by a 'doctor', who writes a prescription, which is then passed on to a pharmacist who dispenses the requested medicine. Both the patient and the vendor can manipulate this procedure. Online consultations assume that the questionnaire has been completed truthfully; therefore there is the risk that medicines can be prescribed on false information. Furthermore, the absence of a proper examination by a qualified healthcare professional could result in misdiagnosis or problematic poly drug use (Henney, 2001). Patients also run

the risk that a legitimate doctor may not exist to evaluate the questionnaire, or the questionnaire might not consider enough key information or ask the relevant questions (George, 2006). The final type of online pharmacy described does not require a prescription. The FDA suggests that these sites are probably fraudulent and as such are the subject of criminal investigations.<sup>31</sup>

Littlejohn et al. (2005) also suggest that online pharmacies can be categorised into four groups. The first involve legitimate pharmacies, which are the online equivalent to high street pharmacies (Bostwick & Lineberry, 2007). The second are subscription pharmacies selling prescription medicine, provided a subscription fee is paid (Littlejohn et. al, 2005). Thirdly and most popular, lifestyle pharmacies offer 'lifestyle' medicines direct to the consumer. Generally involving 'online consultations,' people fill out an online form with their symptoms and submit this along with their order and payment details. The final type involves no-prescription pharmacies, which offer controlled substances without requiring a prescription (ibid).

There is clearly a range of different types of websites selling medicines, some of these that operate according to the law in different countries, whilst others appear to be acting illegally. The global nature and scale of the Web means it is difficult to ascertain how many people purchase medicines online. However, there have been attempts in the literature to provide some perimeters for the size and scale of this problem, which will now be discussed.

### **2.7.1. Size of the market for online medicine purchasing**

Studies evidence significant numbers of online pharmacies and increasing numbers of online medicine purchasing. The increase in numbers of online pharmacies suggests that the market for online medicine sales is growing. In accordance with the economics of supply and demand (Smith, 1937) if there was no audience for medicine online such websites would be obsolete. I will also discuss in Chapter Three, the large numbers of illicit websites selling medicines that have been shut down by the authorities, which indicate a thriving market for online medicine sales.

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<sup>31</sup> <http://transcripts.cnn.com/TRANSCRIPTS/1306/30/hcsg.01.html>

Estimates of the number of online pharmacy sites in operation differ. Research in 2007 found 570 websites in the UK selling medicines; however, only 116 were recorded as registered with the GB Royal pharmaceutical Society (RPS) the following year. In 2009, the trademark tracking service MarkMonitor (2009) reported nearly 3,000 websites selling prescription medicine in 2008-9. Orizio et al.'s (2011) systematic review of websites selling prescription medicine suggested it was difficult, if not impossible, to quantify the number of online pharmacies with any accuracy. Pharmacy websites open and close on a daily basis, and some have many URLs or Web addresses, creating confusion over the number of websites that actually exist. In Orizio et al.'s review the articles comprised two types of data: population surveys and case studies on the adverse effects of drugs purchased online. Most of the studies were US-based and focused on specific groups rather than the general population.

The European Psychonaut project (Schifano et al., 2006) monitored the Web, and tracked and documented drug-related websites by using search engines to identify emerging trends. Using both qualitative and quantitative approaches to enhance the clarity of the findings, the study explored emerging trends in recreational drug abuse. A case study from the project examined both street-market (police seizures and health records) and cyber-market (website text) indicators for phenethylamine 2C-T-7 (Schifano et al., 2005). A contrast was found between the small amount of available information on this recreational drug from street-market indicators and the large amount of online available information, leading the authors to conclude that the Web offers a wealth of drug-related data ahead of what is available to clinicians and regulatory authorities. The same project also explored the uncontrolled availability of prescription medicine online. 275 websites returned from search engine queries were investigated, with nearly one in three (29.6%) offering prescription medicine for sale (Littlejohn et. al, 2005). However, this study only used a single search term '*prescription drugs*', using a more targeted search might have resulted in greater and more relevant numbers of websites.

There are no official recorded figures of global pharmaceutical sales, but statistics indicate that this is a burgeoning market. The average number of daily visitors to pharmacy sites rose from 32,000 in 2008 to 99,000 in 2009 (MarkMonitor, 2009). The sales estimated from approximately 3,000 sites rose from \$4 to \$12 billion between 2008-2009 (MarkMonitor, 2009). In 2008, the

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RPS also estimated that approximately 3% of the UK population regularly purchase medicine online, whilst population surveys and case studies suggest that between 4% and 6% of the US population bought medicines online between 2000- 2007 (Fox, 2004; Baker et al., 2003; Cohen and Stussman, 2009).

Unfortunately these surveys do not distinguish between prescription and non-prescription medicines. A UK-based survey (Gurau, 2005) found that a third of those questioned had bought prescription medicine online, or were intending to do so. The authors used a semi-structured questionnaire, which was applied to 300 UK consumers of varying age and gender. The participants were recruited from the centres of five large UK cities (with an equal amount of respondents per city) via a random sampling technique. The authors claim this sample is representative of the UK population, though this is not evidenced in the paper.

The 2014 Global Drug Survey conducted during November/ December 2013 was the largest survey of contemporary drug use ever carried out<sup>32</sup>. It surveyed respondents from over 18 developed countries worldwide and received almost 80,000 responses. Respondents were questioned about whether they had ever bought drugs online. The most responses for having purchased drugs online were from the UK with 22%, Denmark was the next most popular country with 19.8%, whilst France and the USA were 14.7 and 14.3 respectively. The rest of the countries, including Australia, Belgium, Germany and the Netherlands also demonstrated emerging numbers for online drugs purchases. As 'drugs' was the catchall term used in this study, these figures include illegal drugs as well as medicines that can be obtained legitimately. Therefore these findings are not representative of online medicine purchasing specifically, but they do provide a fascinating insight into online consumerism and drug behaviours via jurisdiction. Other findings from the study provide information about the prevalence of drug use, though this was not linked with online sales. Ritalin, benzodiazepines, and opioid painkillers were the most extensively used medicines. It would have been useful if the Global Drugs survey had also mapped whether these were items also commonly bought online.

Atkinson et al. explored how the Web has been used for health-related activities in a US study (2009). The authors set out to investigate the

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<sup>32</sup> <http://www.globaldrugsurvey.com/facts-figures/the-global-drug-survey-2014-findings/>

distribution and use of different online health tools via an online survey. Their findings showed that 58% of their sample of Web users reported searching for health information for themselves, 3.8% used online support groups, and 12.8% had bought medicine or vitamins online in the past year. Their analysis also found that those seeking health information were more likely to be women, and also that those in the 35-49, 50-64 and 65-74 age groups, along with those who were married, were more likely to purchase medicine or vitamins online.

Inciardi et al. (2010, 2009) conducted studies looking at various population, college and patient programme surveys of diverse demographics (age, race, gender, location and employment) across the US. The authors claimed that although the Web is a tool for obtaining prescription medicine, more purchases probably occur at the wholesale level. Other scholars have attempted to investigate drug trends online. Nielsen and Barratt (2009) conducted a review of literature concerning prescription medicine misuse, but did not clearly indicate how their articles were selected. The review is, however, valuable for identifying how the growth of supply and certain drug trends (via the monitoring of public online discussion forums) can be achieved through search engines. The authors give the example of a feasibility study which developed a systematic approach to analysing online forum discussions for prescription opioid abuse-related content (Butler et al., 2007).

### **2.7.2. Types of sales within the online medicine market**

A number of studies have analysed both the numbers of websites selling medicines and the procedures that consumers undertake in order to procure them. Orizio et al. (2011) undertook a systematic review of the literature on online pharmacies. Table 2 shows some of the articles they analysed based on their use of original data and direct reference to purchasing from the Web. They are presented in chronological order so as to compare the numbers. It is also worth noting that these studies focus on websites that present themselves as pharmacies, selling (specific) prescription only medicines. These numbers do not necessarily include sites that sell OTC and complimentary medicines, herbal remedies, supplements or illegal drugs. The number of websites selling medicines is probably much higher than these studies suggest. Furthermore some of the studies are out of date in that they do not represent the current

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Web, for example in the intervening period the dark web has evolved. However, the table shows that online pharmacies have continually been a topic of interest for nearly 20 years, as well as the trends in certain medicines offered for sale. In the late 90s the focus was on erectile dysfunction treatments, whilst painkillers (specifically opiates) were more popular in the 00s. However, later studies have returned to looking at lifestyle medicines including erectile dysfunction and slimming treatments, suggesting that these are once again the substances most likely for sale (and purchase?) online.

Table 2 Studies identifying numbers of online pharmacies (Source: Orizio et al., 2011)

Author	Year of data collection	Number of online pharmacies analysed	Online pharmacy selection method	Inclusion criteria – only websites selling:
Armstrong	1999	77 SE		Sildenafil
Bloom et al	1999	46 SE		
Eysenbach	1999	22 SE		Viagra
Bessel et al	2002	104 SE		
Forman	2003	53 SE		Opiates
Bloom et al	2006	144 SE		
Arruanda	2004	113 SE		
Mommel et al	2005	4 SE		Contraceptives
Forman et al	2006a	25 SE		Opiates
Forman et al	2006b	50 SE		Opiates
Forman et al	2006c	50 SE		Opiates
Cicero et al	2008	47 SE		Opioid analgesics
Mainous et al	2009	138 SE		Antibiotics
Orizio et al	2009a	118 SE		
Orizio et al	2009b	57 SE		
Raine et al	2009	46 SE		Analgesics
Bate et al	2010	55 SE		Liptor, Viagra, celebrex, Nexium, Zoloft
Gallagher et al	2010	44 SE		Viagra
Orizio et al	2010	175 SE		

\*SE = Search Engine

The purchasing criteria used by the websites included prescription requirement, money-only transaction, management of an online questionnaire, credit-card-only transaction and no original medical prescription requirement.

Some websites require an original medical prescription before prescription medicines can be purchased (Wagner et al., 2001); however, others use online questionnaires reviewed by clinicians or pharmacists (Armstrong et al., 1999;

Bloom and Lannacone, 1999; Bloom and Lannacone, 2006; Eysenbach, 1999). Eysenbach's study of online pharmacies selling Viagra involved posing as a patient in order to buy the medicine. While completing the online questionnaires, the researcher included characteristics that contra-indicated the approved use of Viagra, such as taking other medicines and being the wrong gender. 30% of the websites issued prescriptions anyway. In 80% no history was requested, in 70% inappropriate medical terminology was utilised and in only two cases did a physician review the order form. Other websites were found to have no conditions attached, and made no stipulation of a necessary prescription or assessment (Gernburd and Jadad, 2007; Memmel et al., 2006; Schifano et al., 2006). A Columbia University study also discovered that a 13-year-old was able to purchase the stimulant medicine Ritalin from a website (NCASA, 2010).

Existing research provides some (wide) estimates of the scale of online medicine purchasing. Contrasting methodologies provide differences, and so it is difficult to ascertain the meaning of the statistics and to synthesise them in order to identify common trends and themes. In addition there is also the problem of who is actually making the claims, especially when relying on survey data (Bertrand & Mullainathan, 2001). However, the literature does indicate that there appears to be a large number of websites selling medicines, and this is a growing area of consumerism. This discussion has demonstrated that a clearer understanding of the types of websites selling medicines is required; this will provide insight into whether people are engaging in unauthorised and 'risky' behaviour.

The chapter now turns to the literature investigating who is purchasing medicine online.

## **2.8. Characteristics of the online medicine consumer**

In the previous discussions there has been some consideration as to who are the target for online pharmacies. Liang and Mackey (2009) claim that the target audiences of online pharmacies, the vulnerable groups such as seniors and minorities, are the main purchasers of online medicine as they are either naive to the risks or because they lack the ability to obtain medicines elsewhere due

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to price issues. This presents a picture of people who are not choosing to illegitimately purchase medicines online, either from a lack of insight or necessity.

The Fakeshare project, which investigated the behavioural and psychological factors linked with online medicine purchasing, addressed the knowledge and prevalence in three European Countries: Italy, Spain, and Portugal via an online survey (Fakeshare, 2015). The project found that people in Spain were less likely to know about the possibility of buying medicine online, however awareness of the associated risks was similar across the three countries. Italy had the largest amount of online medicine purchasers, with people living in big cities purchasing more than those living in small towns or country villages. In Spain, males tended to have a more positive attitude towards online medicine purchasing and to perceive it as safer than females do. Driven by the Theory of Planned Behaviour, the project views the purchasing of medicine online as guided by rational beliefs. However, this deductive approach is based on limited interaction with consumers. My study builds on the single methodologies previously used to explore buying medicine from the Web and encompasses the perspective of the consumer via an inductive mixed methods approach.

Littlejohn et al. (2005) state that there are three prerequisites to using an online pharmacy – literacy, Internet access, and credit card ownership. Using the Web to order medicine necessitates basic literacy and numeracy skills. They claimed that socioeconomic deprivation increases the probability of literacy levels being low (Fawcett, 2003) and as such it is more likely that people from higher socioeconomic groups have the skills to use the Web (Littlejohn et al., 2005). However, this is rather simplistic and overlooks the ubiquity of recent Web use along with the measures to bridge the ‘digital divide’ (Norris, 2001). Of course, without access to the Web it would not be possible to use online pharmacies. Littlejohn et al. (2005) found that those in employment had twice the web access as the unemployed, and home owners were more likely to have web access than renters. Again, these assertions can be contested, in the ten years since this article was written more and more people (especially in the UK) are renting and/ or seeking employment, yet web use has increased, with 38 million adults (78%) in the UK accessing the Web every day in 2014, which is 21 million more than in 2006 (ONS, 2014). Although there are a few US based



online pharmaceutical programmes, notably Health Solutions Network, who have provided cash-on-delivery payments when their card processing systems have failed, card payments are traditionally used in transactions with online pharmacies (McCoy et al. 2012). Littlejohn et al. (2005) again disregarded persons from low socioeconomic backgrounds on the basis that they struggle to obtain credit (Palmer & Conaty, 2003), however, this does not account for debit cards and the fact that some online pharmacies now accept paypal.<sup>33</sup> McCoy et al. (2012) in their study exploring whether payment interventions can disrupt abusive advertising, such as Viagra spam, discovered some online pharmacies attempting to use alternative payment mechanisms including PayPal and, most recently, Bitcoin. However, the authors claim that these endeavours have not been that successful, with consumers preferring to use the traditional payment methods.

According to Littlejohn et al. (2005) the people most likely to use online pharmacies are the socioeconomically privileged, with high levels of employment and educational attainment. Such individuals are also identifiable as expert patients, who having used the Web to source their health information have specific (often unrealistic) expectations for their healthcare (Shaw & Baker, 2004). This unflattering caricature of the dissatisfied middle-class consumer, suggests a group likely to self-diagnose from online health information, who will visit online pharmacies when their treatment demands are not met (Littlejohn et al., 2005). If this is accurate then the Web has introduced a new deviant behaviour, that of illicit online medicine purchasing among the higher socioeconomic groups. Though the negative implications of otherwise respectable individuals may not be that obvious, the stereotypical image of lower class problematic substance user might be challenged. This depends on whether or not people respond to the risks and distinguish between legal and illegal online medicine purchasing, which challenges Fittler et al.'s (2013) study.

Although the literature provides some demographic information this is a limited one-dimensional portrayal of the online medicine consumer. In order to appreciate the nuances involved in online medicine purchasing, it is evident that we need to move beyond reducing individuals to mere characteristics and

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<sup>33</sup> <http://www.ppacepted.com/pharmacies.html>

develop the person and their identity. Therefore an investigation into who is purchasing medicine online is required. In presenting both quantitative information on online medicine purchasers and their qualitative accounts, this thesis will provide a greater understanding of the online medicine consumer.

Building on this, identifying the drivers to online medicine purchasing is essential to obtaining an informed understanding of the issue. Some studies have investigated the reasons why people are engaged in this practice. The chapter now turns to benefits that drive online medicine purchasing.

## **2.9. The benefits of purchasing medicine online**

Online prescription medicines are regarded as cheaper for consumers, than if they were purchased offline (George, 2006). In the US for example, unregulated medicine prices and strong patent laws have culminated in high medicine costs. There has been a long tradition of US citizens visiting Canada to stock up on their lower priced medicines, and this is also reflected in sales from Canadian online pharmacies (ibid). However, Weber's (2000) study found that certain medicines bought online were not cheaper than the traditional offline sources, especially when shipping and handling costs were factored in.

A US study conducted by Forrester Research found the following motivating factors for using the Web to purchase prescription medicine: order during off-hours (59%); saves time (50%); easier than mail order (50%); cheaper (44%); cuts trip to the pharmacy (41%); refill reminders (26%); online medication information (23%); customer service (20%) (Fung et al. 2004). The wide selection of medicine online provides increased choice for consumers, which allows them to easily compare prices. Cost was also a prevalent factor in a 2003 UK study by The National Audit office, where consumers stated that they were buying prescription medicine from the Web because it was cheaper (NAO, 2003). This research also found people expressed that the ease of obtaining prescription medicine without a prescription was appealing (NAO, 2003). Bessell et al. (2003) found that despite cost being a major driver of online medicine consumerism, there were large price disparities between medicines being sold by difference online pharmacies in different locations. Bessell et al

(2003) suggest that consumers would be more inclined to benefit from cost savings by making bulk orders, although the study was unable to ascertain whether people buy more products than those required at the time. This could be a reason to purchase multiple items or make larger orders, rather than the presumption of criminal activity in ordering extra to sell them on as suggested by Lavorgna (2015).

However, price is not the only significant motivation. Liang and Mackey (2009) claim that some consumers buy medicine online, because they perceive that the benefits outweigh the supposed dangers. Convenience and ease are important as the availability of medicine online means that medicines are accessible 24 hours a day 7 days a week, which has huge benefits to disabled people, those living in remote areas, and those who have problems travelling to a doctor or pharmacy (George, 2006).

An online UK survey suggested that speed, convenience and cost are primary motivators. This survey, conducted by Banks et al. (2009), involved 935 men aged over 35 years and assessed their attitudes towards counterfeit medication. The study was focused on Viagra and so only provides a limited perspective of the particular demographic at which this medicine is aimed. As such, women and men younger than 35 were excluded, even though they may try to purchase and use this medicine too. An earlier study by Bellman et al. (1999) suggested that those with hectic lifestyles were more likely to purchase items from the Web, although the survey was about all purchases, not just medicines.

The Web can also afford privacy to consumers who are reluctant to shop in public places. Makinen et al. (2005) and Levaggi et al. (2009), in their studies of online pharmacy reviews, suggested that confidentiality and desire to avoid the doctor are important factors in people choosing to purchase their medicine from the Web. Anonymity online may allow consumers to ask questions regarding conditions and treatments, which they may otherwise be too embarrassed to enquire about in person (George, 2006). In addition, Shabsigh et al.'s (2004) study of erectile dysfunction treatment made the claim that consumers may choose online pharmacies because they believe that their condition is not serious enough to warrant medical attention. Seeberg-Elverfeldt (2009) suggests that people may turn to the illegal online

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pharmaceutical trade in order to obtain products they are no longer able to obtain, for example medicines to treat sensitive issues such as impotence, anonymously elsewhere.

Jurisdiction may also play a key role in motivating online medicine purchasing. The current global economic crisis has left many people uninsured and/ or lacking the means to access essential healthcare services and medicine (Centre for American Progress Action Fund, 2009). The Web may represent an attractive alternative to the traditional forms of healthcare that may be expensive or inaccessible. Also the same vulnerable patient populations likely to benefit the most from online healthcare are the target audience for illicit online pharmacies (Liang & Mackey, 2009). Vulnerable patient groups have also turned to the Web because they have been otherwise unable to access the medicine they need. Wilkinson (2006) found that some patients with cancer ordered medicine online because they were unable to access the treatment in the UK.

The literature considers some of the motivations for purchasing medicine online, however, some of these studies are focused on specific types of medicine. Others are limited to particular countries, for example the US. The majority of these studies rely on quantitative survey data, which do not offer a detailed exploration of the reasons for purchasing. Therefore it is necessary to undertake further investigation into the drivers for online medicine purchasing.

## **2.10. Summary**

This chapter has considered the novel opportunities that have arisen from medicine being available to purchase online. The main impact that the Web has had on the provision of medicine is in enabling new forms of consumerism. Although the issue of obtaining medicine from unauthorised sources pre-dates the Web, purchasing medicine online is providing a new source for legal and illegal medicine purchasing. The chapter showed that the legality of online medicine purchasing is contested. The literature suggests that some people may be unaware of the legal status of online medicine purchases. For others the Web may be a route to illegal or illicit drugs. However, the literature does

not address how people are finding out about online medicine purchasing and whether they are using legitimate means, which could impact on how people construct or react to risk. This provides the basis for research question 1. *What are the routes for online medicine purchasing?*

The existing literature suggests an increase in the types of medicine available to purchase. Although many studies still focus on lifestyle medicines, there appears to be an increase in other types of prescription medicine and substances that emulate illegal drugs. This area still requires investigation to identify the current trends in types of medicine purchased online, and their types of classification, which will allow us to understand how online medicine purchasing is constructed in terms of risk. The literature suggests that significant numbers of people are purchasing medicine online from different types of websites that trade legitimately and illegitimately. However, it is difficult to identify common trends and themes from the contrasting literature. This necessitates research question 2. *What types of medicines are available for sale online and what types of websites sell these medicines?* to build on existing knowledge.

The literature discussed provides background for research questions 3. and 4. *Who is purchasing medicine online? and What drives online medicine purchasing and how can we better understand the practice?* It helps to identify demographic details of the online medicine consumer and to inform my examination of people's accounts of online medicine purchasing. However, most of this evidence is descriptive survey research and there is a lack of qualitative approaches, which could offer more detailed understanding of online health behaviours. This has influenced my decision to undertake a mixed method methodology. Previous studies have provided some insight into the perceived benefits of online medicine purchasing, such as cost, convenience, privacy, and jurisdiction, but they have not considered the ways that purchasers construct risk. This thesis will address this gap in the literature and the next chapter focuses on the 'risks' of purchasing medicine online.



### **3. Understanding risks and deviance when thinking about online medicine purchasing**

This chapter looks at how the ‘problem’ of purchasing medicine online has been framed as risky. Research and policy about online drugs and illicit markets, is discussed looking in particular at how authorities have responded to these risks. The chapter draws on the work of Erving Goffman to understand how deviant behaviour is recognised and managed as a way of understanding responses to risk, before considering these ideas in the context of the Web. This chapter provides the foundation for the theoretical framework for analysis to meet objective 5. *Apply a theoretical framework for analysis*, which aims to underpin research question 5. *How do people engaged in online medicine purchasing view their conduct once aware of it being constructed as risky and problematic by external agents?* This objective will be supported with the empirical data of people’s accounts of online medicine purchasing in later chapters in the thesis.

#### **3.1. The risks of purchasing medicine online**

There are specific risks associated with purchasing medicine online regardless of whether the transaction is legitimate or illegitimate, which have been highlighted by governmental agencies and the media. However, purchasing prescription-only medicine without a prescription online, may expose the consumer to a greater likelihood of such risks occurring (as Fig 1 in Chapter Two demonstrated). Counterfeit medicine, criminal activity and health implications have been intertwined with the discourses on the pharmaceutical marketplace, governance, and health expertise. Each of these issues will be addressed in more depth.

##### **3.1.1. Counterfeit medicine**

The World Health Organisation has identified the public health risk connected with counterfeit medicines being sold on the Web in a number of publications

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(WHO, 2009, 2010a, 2010b). The combination of demand and ease of online sales ensures that there are an abundance of sellers who supply fake, substandard, tainted, unapproved, misbranded, poor quality medicines on the Web (Mackey & Liang, 2011). The impact on global health from counterfeit medicine can be extreme, with anti-microbial resistance in fatal diseases such as malaria, HIV and tuberculosis, resulting in hundreds and thousands of deaths in developing countries (Kennedy, 2011). Globally, counterfeit medicines are presented as a serious threat to the safety and quality of the legitimate supply chain and the Web is a cost effective and accessible route to illegal market entry and distribution (Mackey & Liang, 2011).

Whilst academic work and investigative reports affirm the existence of thousands of websites selling counterfeit medicine (Arrunada, 2004; Orizio et al. 2010, TRANSCRIME, 2010). Estimates suggest that the proportion of counterfeit medications sold over the Web ranges from 44% to 90% (Jackson et al., 2010). According to Jackson (2009) the criminal market in counterfeit medicines is estimated to be worth 75 billion dollars per year. This corresponds to approximately 10 percent of the global trade in medicines. However, the prevalence of counterfeit medicines relates to jurisdiction, for example Cahoy (2008) claims that there is a 'north-south' divide. In developing countries approximately 30 percent of medicines are thought to be counterfeit (Dondorp et al., 2004; IMPACT, 2008), whilst in developed countries the estimates are less severe, with less than one percent of medicines presumed counterfeit. This is where the Web plays a negative role, as it is considered to be the main source in which counterfeit medicines infiltrate the markets of developed countries, as the legal production and supply chains are otherwise protected by effective control polices (Bate, 2012). Particular countries have been recognised as problematic within the online pharmaceutical trade; for example, over 60% of substances sold in Nigeria, some via the Web, were found to be counterfeit (Wall, 2007).

Fung et al.'s systematic review of websites dealing in counterfeit medicines identified 130 articles, many of which reported legal cases involving an online pharmacy (2004). Viagra, as the medicine of choice, also features



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disproportionately in studies on counterfeit medicine (Kahan et al., 2000; Baert and Spiegeleer, 2010). Jackson et al. (2010) examined the counterfeit market for erectile dysfunction (ED) medication, and determined that 67% of men who purchase prescription-only medication for ED without a prescription do so using the Web.

Even though there is widespread concern about the online counterfeit medicine trade, there has been some criticism that this issue has been under-investigated by criminologists (Lavorgna, 2015), with claims that it is a serious transnational crime that does not receive the attention it deserves (Attaran, 2011). Currently the academic work that has investigated this area comes from disciplines such as medicine or health sciences.

#### **3.1.2. Criminal Activity**

This section outlines the role of the Web in accelerating and magnifying the sale of medicines. In addition to risks concerning the quality of medicine, purchasing medicine online can lead to criminal activity that includes ID and credit card fraud, PC viruses and links to organised criminal networks. However, Leyden (2005) contends that ID theft is actually a misnomer, as it concerns impersonation fraud rather than the theft of an individual's identity. It is a crime against the vendor rather than the consumer, so should be regarded as retail theft. However, when a consumer is affected by such fraud, there is the likelihood that their credit rating or bank status could be impaired.

The sale of prescription medicines through websites provokes widespread concern because of the potential dangers that can arise from the circulation of unregulated or even counterfeit drugs linked to organised crime (Hall, 2005 in Wall, 2007). Wall (2007) points to the Viagra trade; many Viagra emails are thinly-veiled attempts either to link to spam or to infect computers with Trojans. By clicking on these emails, people unwittingly allow unauthorised access to their computers and personal information, thereby making them vulnerable to loss or theft of data/finances.

The Web has opened up a new opportunity for people to purchase medicines including those that they are not authorised to obtain otherwise. Although the illegal consumption and purchase of medicine and drugs is not a new

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phenomenon, it is one that the Web appears to enable or magnify. The global reach of the Web, accessibility of online purchasing and associated possibilities of anonymity or concealment has made this an important avenue for illegal drug trading. As Schneider and Sutton (1999) point out, the nature of the Web means that these “crimes” are difficult to detect or prosecute. The illicit sale and distribution of pharmaceuticals has been traditionally undertaken without the use of computers or associated networked technologies. The Web has changed this; indeed, Wall (2007:45) claims that the online practices of drug dealers constitute a first-generation of cybercrimes. First-generation cybercrimes also exist independently of broader networks, and so if computers and online networks were hypothetically removed, then the activity would persist by other means (Wall, 2007:45).

Calderoni (TRANSRIME, 2012) refers to the ‘dual nature’ of the pharmaceutical market, which consists of both legal and illegal components that apply across countries and regions relating to cultural, social and economic factors. Transactional drug distribution would occur as it did before the Web, involving large-scale drug supplies and distribution through complex criminal networks, depending on multiple layers of importers, wholesalers and street-level dealers (Pearson and Hobbs, 2001). However, Wall (2007) also talks about second-generations of cybercrime, where crimes are committed across networks. These are essentially traditional crimes for which novel globalised opportunities have emerged due to the Web.

The anonymity of the Web allows for criminals to hide behind various layers comprising of underlying service providers. This makes identifying the owner of illegal sites problematic. Online pharmacies can mask their details using registrar or listing companies in their domain registrations (Mackey & Liang, 2011). Furthermore, they can provide links to more illicit forms of activity such as illegal drug purchasing (ibid). Therefore, even if a website is trading illegally, it can be difficult to determine ownership and location, making law enforcement difficult.

As well as being a major player in driving ecommerce, the pharmaceutical market has also been highly attractive to organized crime groups (Riccardi et

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al.2014). Illicit online pharmacies threaten state sovereignty and global security via their affiliation with transnational organised crime syndicates, along with cybercrime and cybersecurity issues. The link between the online drug trade, which includes online pharmacies, and organised crime is highlighted by the case of the Archiveus Trojan in 2006, where a female computer user found that her files had been corrupted/encrypted with complex passwords. She was instructed by blackmailers not to contact the police but to buy drugs from an online pharmacy where she would discover the password (Oates, 2006). Lewis (2003) has therefore described the emergence of illicit online pharmacies as a highly significant type of cybercrime, which is a major challenge in contemporary society.

#### **3.1.2.1. Online drugs and illicit markets**

Distinctions may be drawn between the “Open” web and the “Dark” web. The open web refers to webpages that can be easily found via search engines such as Google. However, certain content online is purposely concealed and is accessible only with special software, such as Tor, which enables users to communicate anonymously online. This part of the Web has been referred to as the dark web and has been utilised for both legitimate and criminal activity, including the distribution of illegal drugs. One such distribution company, called Silk Road, has received much attention from the media and academics (Chen, 2011) and was closed down by the FBI. However, the threat of prosecution has not deterred other vendors, and other clandestine outlets have replaced it, including the imaginatively titled: Silk Road 2.

The United Nations Office on Drugs and Crime’s (UNODC) 2014 World Drug Report addresses the expansion of online drugs markets, particularly those on the dark web or the ‘hidden web.’ It claims that these markets have “the potential to become a popular mode of trafficking in controlled substances in years to come.” The report sets out that there are increasingly a large variety of drugs available for sale on the dark web. Due to the sophistication of contemporary technology and the growing specialisation in online supply networks, traditional approaches are ineffectual against the modern drug trade. Enforcement efforts via surveillance, hacking and other forms of intervention have proved successful in closing down individual sites, but are

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unable to prevent similar sites from opening elsewhere. Aldridge and Decary-Hetu (2014) describe online drugs markets as a “paradigm-shifting criminal innovation.” Whereas violence was prevalent within the street drug trade, the anonymity and the virtual spaces of online drugs markets eliminates the need and the feasibility of resorting to violence.

According to Schifano et al. (2003) traditionally there are two types of illicit drug markets. The first is the ‘street market,’ which usually deals in heroin and cocaine and is run by hierarchical crime organisations, with the threat of violence omnipresent. The second is the ‘free market,’ which involves peer-to-peer selling of cannabis and ecstasy. This notion that the roles of the vendor and consumer are shifting online was also considered by Lavorgna (2015), who discussed this new trend in the online criminal pharmaceutical market. Extending the traditional activity of sharing medicines and making it a commodity, there are instances where medicines are bought online in order to be resold. This has been confirmed by law enforcement agencies in Lavorgna’s study (2015), which have noted the larger quantities of pharmaceuticals in packages they intercept. Some online pharmacies advertise on their websites that they will divide large orders into smaller shipments. Therefore packages may avoid detection or be interpreted for personal use, and thus ignored by the authorities. Hence the risks of joining the illicit online pharmaceutical markets are low (Schifano et al. 2003).

However, the Web has potentially introduced a third market, the Ecommerce market, where all types of substances are easily available to buy online (Schifano et al 2003). Holt (2012), in a study investigating the forces shaping cybercrime markets, claimed that much like other ecommerce trading, price, customer service and trust influence the relationships between vendors and consumers in these markets.

In order to reach as large a number as possible of likely consumers, illegal and illicit medicine trading is conducted via the open web (Lavorgna, 2015). However, investigations of Silk Road have discovered that the medicines with the greatest potential for abuse are also sold on the dark web (Van Hout & Bingham, 2013b). It has been suggested that some pharmaceuticals are often

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sold in conjunction with synthetic drugs to even out or heighten their effects, a form of poly-drug use (Parker et al. 1998). Consequently, similarities and links between online markets may be inevitable (Schneider, 2003; Barratt, 2012). Although media reports on dark web markets focus on illegal recreational drugs such as heroin and ecstasy, Bartlett (2014) claims that some of the top-selling items are prescription medicines. In 2015 there were 3,966 listings for “prescription drugs” on Silk Road 2.0: compared with 1,728 for psychedelics and 1,267 for ecstasy (ibid). This demonstrates how online drugs markets have opened up the accessibility of substances, and moreover, that prescription medicine is a more highly traded entity within the dark web. Whilst Class A drugs are available from street dealers, often prescription medicines are not so readily attainable from such sources.

The European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) Trendspotter study (2015), focusing on the Internet and Drug markets, suggests that it is improbable that online pharmacies are used as a main supply for illicit drug markets. Furthermore the indication is that the emerging expansion of cryptomarkets on the dark web is a more reliable and cheaper alternative to criminals.

Amongst the negative discourses on online drugs markets, there are claims that they are the best sources of peer-to-peer harm reduction advice (Van Hout & Bingham, 2013a, 2013b). Many people purchase drugs from darknet sites where vendors can be rated (Van Hout & Bingham, 2014), and so substances tend to be of a better quality and as advertised, to avoid bad reviews and loss of sales. This approach is based on consumer trust as they rely on credible information to pass through the communities. Unlike street markets, where traditionally there has been little trust between buyer and seller, the risk of physical exposure and arrest, and the threat of violence, online drug markets reduce such barriers to purchasing. However, consumers are presented with a veritable ‘sweet shop’ of substances, far more than they would be offered from a street dealer, which could encourage experimental usage of hitherto untried substances (Harocopos & Hough, 2011).

Counterfeit medicines are inextricably linked with online drugs markets. The intricacy and global scale of the online counterfeit medicine trade implies

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organisation by highly sophisticated criminal networks (Satchwell, 2004; Grabosky, 2007; Attaran et al., 2011; Interpol, 2012; IRACM, 2012). Attaran et al. (2011) also claim that the lenient punishment for this type of criminal activity makes it less risky than other illicit drug trades. Furthermore the market for medicines is greater than that of illegal drugs, so there is more of a profit incentive driving the online illicit medicine trade.

In a study investigating the online counterfeit pharmaceutical trade, Lavorgna (2014) identified five different types of criminal opportunities made available by the Web. Using a crime script framework, Lavorgna discussed how the Web acts as a facilitator via communicative opportunities, managerial opportunities, organisational and relational opportunities, promotional, marketing, and persuasive and loyalty building opportunities, and information and targeting opportunities. The study highlights how criminals are able to exploit these opportunities and that the Web is altering the characteristics of crime. The Web is used as a persuasive tool to make consumers feel part of the same social group; it adds a new layer to the trafficking of counterfeit medicines by targeting communities with shared needs (Lavorgna, 2014). Online groups and social networks, such as in forums, are exploited to advertise and sell illicit medicines. In accordance with the literature on consumerism (Bart et al. 2005), specific types of individuals from the same social groups as the vendor, who share similar values systems and beliefs are zeroed in on as they are inherently more prone to trust them (ibid), for example athletes wanting steroids, or slimmers wanting diet pills.

Having discussed the attributes of online medicine purchasing that have clear criminal connotations and are punishable by criminal laws, I now consider how those with vested interests to control those that occupy them, have criminalised civil online spaces. I will show how this fits into the argument of how online medicine purchasing has been constructed as a risky behaviour.

### **3.1.2.2. The criminalisation of civil online spaces**

Previously non-criminal online spaces have effectively been criminalised in order to regulate behaviour deemed problematic by the authorities. For

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example states have criminalised the technologies and people that use them to promote alternative political activities (Cere, in Jewkes, 2013), because such activity threatens hegemonic ideologies. Thus, in an early example of the criminalisation of online spaces, the French Government blocked blogs and websites during the civil unrest in October 2005, as they were deemed to be fuelling the crisis. Blaming web spaces for social problems suggests a technologically determinist view of the Web, which overlooks the root causes that are often within society itself. More recently online activities during the London Riots of 2011 were singled out and criminalised (Briggs & Baker, 2012; Fuchs, 2012; Tonkin et al. 2012). Individuals making posts on social media regarding 'meet-ups' to start further riots in other areas were prosecuted. As these did not come to fruition, their status as 'criminal' acts is debatable as there is no evidence to prove that these were not just created for mere 'entertainment'. As Wall has claimed: "*many of the behaviours that have been identified as cybercrimes are not actually crimes as such but invoke civil remedies instead*" (2001:3).

The blurring between civil and criminal law is also evident when considering how music downloading has been constructed. David (2010) argues that networked technologies such as peer-to-peer file sharing, has democratised music consumption by allowing increasing numbers of producers and consumers to engage more equally than under previous centralised establishments. This transformation threatens the authority and the profits of the record industry, whose response has been to criminalise the sharing process. Intellectual property rights have been applied to legally restrict the circulation of music online, in order to control its use. However, due to the distributed nature of peer-to-peer networks, combined with technological failures to prohibit unauthorised downloading of music files, attempts at control have been largely unsuccessful (David, 2010).

As highlighted through this thesis, the purchase of medicines (as opposed to drugs) is governed by regulations that carry no criminal sanctions for the consumer, as laws only apply to sale and supply. Therefore, web spaces that consumers of online medicine occupy are civil spaces. However, parallels can be drawn with the examples above, as to how these civil spaces have been criminalised by those with vested interests. In the first instance the drug

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manufacturers have added to the construction of the criminalisation debate by suggesting that online medicine consumers are at risk of fuelling the counterfeit medicine trade. Just like the record industry, the profits of the pharmaceutical industry are threatened by the expansion of choice online. Their attempt to dissuade people from taking advantage of such opportunities is to highlight the links with criminality. A purpose of criminalisation is to gain or maintain control. This is demonstrated in the approach by the regulatory authorities, such as WHO, the MHRA and the GMC, whose governance is threatened by the ability of consumers to avoid medicine regulation. Purchasing prescription only medicines without prescription online has been presented as though it could be an illegal act in various campaigns<sup>34</sup>. These campaigns do not necessarily stipulate that the purchasing itself is illegal; yet, neither do they inform consumers that they are not at risk of prosecution, even if they purchase prescription only medicine without prescription. Naturally, regulators would not want to further encourage online medicine purchasing, whether legitimate or illegitimate, by promoting it as a legal activity (and certainly the misnomer of 'legal highs' demonstrates the potential problems that could arise). Nevertheless, the emphasis on danger and risk is constructed in terms easily interpreted as criminality. However, as solutions to extinguish music downloading has floundered, so too have attempts to criminalise online medicine purchasing, as global networks challenge national regulatory boundaries, and people are able to comfortably circumnavigate legislative controls.

Healthcare professionals are also part of the criminalisation debate as online medicine purchasing enables their expertise to be neglected, or completely left out of the process. It is this expertise that is emphasised by the regulatory authorities in their campaigns, with people who avoid the consultation with their doctor before obtaining medicine online, portrayed as vulnerable to

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<sup>34</sup> <http://www.interpol.int/Crime-areas/Pharmaceutical-crime/The-dangers>  
<https://www.youtube.com/watch?v=290jb9hV2vU>



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potential health risks. Thus civil and criminal law blur as spaces for online medicine purchasing are constructed as risky places to engage with.

#### **3.1.3. Health implications**

In a review paper exploring the online pharmacy industry, Weiss (2006) suggests that online pharmacies bypass the safeguards of the doctor-patient relationship and create a dangerous opportunity for prescription drug abuse. Manchikanti (2006) also suggested that the Web supports the abuse of prescription medicine in a comprehensive health policy review of the written and oral testimony of witnesses at a Congressional Hearing. The review discusses how online sales of psychoactive prescription drugs, in particular, have become a major enterprise, and are presenting new challenges to drug abuse prevention and treatment in the US. Another study, which surveyed US citizens attending treatment centres, indicated that 6% of respondents had used the Web to buy prescription medicine to feed their addiction (Cicero et al., 2008).

A further US study also suggested that the Web has become a source of controlled substances for some addicted individuals (Gordon et al., 2006). This preliminary study employed semi-structured interviews to obtain data regarding the way drugs were obtained. Their sample consisted of 100 adult drug-dependent inpatients in a private residential treatment program. 29% reported knowledge of the Web as a source of drugs, and 11% reported that they had used the Web either to buy drugs or to locate a drug dealer.

There are no reliable statistics on side effects or harms resulting from medicines bought online. In 2007 it was reported that the FDA did not have accurate figures on 'adverse events' resulting from online medicine purchases (Easton, 2007). A UK survey reported that one in four general practitioners said that they had treated patients for adverse reactions to medicines bought online, while a further 8% suspected they had treated side effects of web-bought medicines (Moberly, 2007). However, the survey did not ask whether the medicines that caused these reactions were purchased abroad or from unregistered outlets, or whether the reactions were the result of fake drugs, a failure in the instructions provided or an interaction with another medication.

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Estimates on deaths per year caused by counterfeit medicine range from 100,000 to 700,000 (Bate, 2012, Harris et al., 2009). In China during 2001 it was reported in the Shenzhen Evening News that 200,000 people were alleged to have died from consuming fake medicines (Satchwell, 2004:44; Humble, 2005). There have also been reported deaths occurring from the consumption of counterfeit medicines bought online (Kao et al., 2009; Dondorp et al., 2004; Hanif et al., 1995).

Furthermore, cases such as that of Eloise Parry, where a fatality has occurred after purchasing medicine online, are not unique. In 2013, a young British woman died after taking slimming pills that she had purchased online. In both cases it is significant that the product taken was not sold for human consumption in the US or UK. This highlights another predicament concerning substances that up until recently escaped medicine regulation provided they were not marketed for human consumption. Sold under the guise of bath salts or plant food, though the design of their packaging and marketing may suggest otherwise, so-called 'legal highs', as they are commonly called, are novel psychoactive substances (NPS) that were previously not controlled under national regulations.

Some researchers also believe that deaths attributable to online medicines have been overlooked or wrongly recorded (Townsend, 2009). Crocco et al. (2002) reviewed reported cases of harm associated with the use of health information and found only one reported case. The case involved the death of a 55-year old cancer sufferer, who, after obtaining information online, self-medicated by consuming medicine purchased from an alternative medicine website for four months. Liang & Mackey (2009) claim that the amount of documented patient injury and deaths in numerous countries directly associated with medicine purchased online, involving both substandard and counterfeit medicines, and medicine consumed incorrectly, provides evidence of ongoing patient safety risks that justify regulation and enforcement.

There are claims that healthcare professionals can help to reduce the risks associated with online sales of medicines by taking a pragmatic approach. In a 2010 report from the Nuffield Council on Bioethics, it was suggested that

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doctors should be trained in how to advise people who look up health information and want to buy medicine online (McGauran, 2010). The report also called upon the government to provide high quality health information online to ensure that valuable information is available to patients, and that healthcare professionals should direct patients to these sites.

### **3.2. How have policy makers and authorities responded?**

Different authorities have responded to the issue of purchasing medicines and illegal drugs online. The World Health Organisation (WHO) has also noted the risk of purchasing medicine online in various publications (Videau and Fundafunda, 2000; WHO, 2009, 2010a, 2012b). Due to the continuing public safety concerns that converge between the global public health and technology policy realms, there have been various strategies recommended to combat this transnational form of cybercrime; however, few solutions have accurately dealt with illegal online pharmacies (Mackey & Liang, 2013). National governments have not responded to the problem of illegal online pharmacies with legislation. Instead they rely on the usual medicine regulations that already existed, which fail to recognise online pharmacies as a distinct category (Liang & Mackey, 2009). In a Member State Survey by the WHO Global Observatory for eHealth (GOe)<sup>35</sup> 66% of respondents had no legislation specifically allowing or prohibiting online pharmacy operations. Whilst only 19% of those countries regulating online pharmacies prohibited the illicit trade and 7% allowed it without considering adequate law enforcement provisions. Significantly, developing countries with fewer resources were more likely to have no regulation.

Even if a country has attempted to have a regulatory response to the issue, efforts may be inadequate or ineffective due to the rapidly changing dynamic nature of the Web. For example, the US enacted the Ryan Haight Online Pharmacy Consumer Protections Act<sup>36</sup> in 2008, which regulated the online sale

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<sup>35</sup> [http://www.who.int/goe/publications/goe\\_security\\_web.pdf](http://www.who.int/goe/publications/goe_security_web.pdf)

<sup>36</sup> <https://www.govtrack.us/congress/bills/110/hr6353#>

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of US controlled substances, however, this law is limited in scope, as it does not consider the wide range of pharmaceuticals online (Liang & Mackey, 2009). Furthermore it only deals with illicit vendors based in the US, despite evidence suggesting that the majority of these illicit traders are based elsewhere (ibid). There have also been no reported successful prosecutions under the Act, and vendors are undeterred about selling controlled substances without prescription (ibid).

In the UK the MHRA have attempted to inform the UK public of potential dangers via various web campaigns (2013). Working alongside the Metropolitan Police Central E-Crime Unit, and with Internet Service Providers, credit card companies and other relevant stakeholders, they have attempted to terminate illegal web activity in their jurisdiction, for example closing down websites deemed to breach UK regulation. Similar to the restrictions imposed on the US legislation, UK regulation only considers websites trading out of the UK. National authorities are generally powerless to enforce action outside of their own borders (Binns & Driscoll, 2001). In addition, when a medicine has been withdrawn from sale in the UK, but is imported into the country for personal use, the MHRA has no authority to act. The current UK regulatory framework provides no means for the authorities to enforce regulation, because the law only applies to the sale and supply of medicines.

The promotion of illicit online pharmacies is also inadequately regulated by many countries (Lexchin, 2012), thus their populations are exposed to public health and individual safety harms from the direct-to-consumer marketing that the Web provides. Furthermore, the WHO Ethical Criteria for Medicinal Drug Promotion<sup>37</sup> (WHO Criteria) fails to consider the challenges afforded by the Web as a medium for promotion and influencing health behaviour. In addition the criteria is voluntary and so only those acting in good faith are likely to adhere to the guidelines, rather than the criminal actors who want to continue their dominance over the online pharmaceutical marketplace. This does not remove

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<sup>37</sup> <http://apps.who.int/medicinedocs/documents/whozip08e/whozip08e.pdf>

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the risk of illegal medicines offered for sale online, nor does it reduce the temptation for consumers to access them for personal reasons.

In order to tackle the demand as well as the supply, an educational approach has also been attempted, which relies on reaching the target audiences and them adopting the intervention. In the UK the MHRA have published safety information for consumers about buying medicine from the Web. Their main stance is to advise people to consult a doctor or healthcare professional first, rather than using the Web to purchase medicine without prescription. They express caution about purchasing medicine online, especially where the medicine would normally only be available from a high street pharmacy. They also claim that many websites originate from outside the UK and are therefore not regulated by UK authorities, and point out that purchasing prescription-only medicine from unauthorised sources significantly increases the risk of obtaining substandard, fake or counterfeit substances. In order to raise the awareness of potential online medicine consumers the US FDA has devoted a section of their website to 'Buying medicines over the Internet' (US FDA, 2010). With sufficient information, the public can decide whether they want to take the risk in obtaining medicine from the Web.

The relationship between licensed prescribers and online pharmacies is also uncertain. There are licensed big brand name stores that operate online as they do on the high street, and also online pharmacies that are licensed to trade. However, there is no overarching accreditation to assist consumers in identifying authentic online medicine suppliers. Instead, registration of online pharmacies is subject to individual national or state validation procedures. All UK pharmacies, including online pharmacies, are bound by a set of codes defined and enforced by the Royal Pharmaceutical Society (RPS). In order to establish the legitimacy of online pharmacies and direct UK consumers to websites that trade legally and safely, the RPS has created a register and logo to be displayed on pharmacy sites. Each website's logo carries a unique registration number. Online pharmacies are required to register with the RPS in order to trade legitimately; however, many do not (George, 2006). Recognising that this is a significant issue, The General Pharmaceutical Council (GPhC)

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launched a consultation to assess the draft guidance for registered pharmacies<sup>38</sup>.

The European Parliament has also attempted to tackle illegal online medicine sales by issuing Directives aimed at expanding enforcement measures and distinguishing illicit actors from legitimate sources by implementing credentialing and a universal logo (George, 2012). What is beneficial about these policies is that lists of suspect websites can be maintained, however participation in these programmes has been minimal, and consumers are not necessarily aware of their value (Mackey & Liang, 2013). The implementation of the EU wide common logo system from Directive 2011/62/EU remains to be seen whether public awareness will increase.

In the US, The Verified Internet pharmacy Practice Sites (VIPPS), a programme of the National Association of Boards of Pharmacy (NABP), provides accreditation to online pharmacies. This approval signifies compliance with state and federal laws and regulations. The accreditation process involves the submission of an application to NABP, a NABP review and verification of a pharmacy license status, and an online survey. Further reviews are conducted annually and reaccreditation is undertaken every three years. To safely buy medicine online, consumers are advised to use NABP approved and VIPPS accredited online pharmacies. Lapidus and Dryankova-Bond (2014) claim that at the time of publishing, there were 36 approved online pharmacies, which provided links to the NABP and VIPPS websites.

With no overriding standards encompassing the sale of medicines online, international cooperation among the various stakeholders is needed. There have been some initiatives undertaken to prevent and oppose the online illicit and counterfeit medicine trade at international level. Annually INTERPOL coordinates Operation Pangea, a week of action combining law enforcement, regulatory agencies and private stakeholders from various countries to crack down on the sale of illicit and counterfeit medicine on the Web. There is

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[http://pharmacyregulation.org/sites/default/files/draft\\_guidance\\_for\\_registered\\_pharmacies\\_providing\\_inter\\_net\\_and\\_distance\\_sale\\_supply\\_and\\_service\\_provision.pdf](http://pharmacyregulation.org/sites/default/files/draft_guidance_for_registered_pharmacies_providing_inter_net_and_distance_sale_supply_and_service_provision.pdf)

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considerable variation in figures for the number of websites that are illegally operating; INTERPOL and the MHRA, during 'Operation Pangea', shut down some 9,610 sites in 2012 and 18,000 in 2011 because they were selling pharmaceuticals that they were not licensed to sell. However, shutting down websites is not cost efficient, both in time and resources, and does not ensure long-term success as websites can re-open under a different name or URL easily.

UNODC has also taken a key role in the global conflict against the online counterfeit medicine trade.<sup>39</sup> The lead UN agency combatting global organised crime networks, UNODC have partnered with the International Narcotics Control board to specifically urge governments to engage in enforcement against illicit online pharmacies.<sup>40</sup> This report also includes an emphasis on the disruption of online pharmacy use of social media marketing targeting young people. UNDOC also features within some of the discourses on Internet governance, and a proposed eHealth governance for cybercrime. The UN-initiated World Summit on the Information Society (WSIS) established the Internet Governance Forum (IGF), they define Internet governance as the establishment of shared principles, norms, rules, decision making procedures and programmes developed by governments, the private sector, and civil society on the use and evolution of the Internet.<sup>41</sup> Focusing on illicit online pharmacy networks, transnational crime and cybersecurity, UNDOC has been suggested to coordinate IGF partner efforts to respond to these issues (Mackey & Liang, 2013). Existing partnerships with INTERPOL, the World Customs Organization and civil society would be coordinated to fight against counterfeit medicines online.

UNODC is also authorised by the UN Convention against Transnational Organized Crime (UNTOC) to address serious global crimes such as human trafficking, smuggling, and illicit manufacture and trafficking of dangerous materials (Mackey, 2013). There has been a recent intersection between

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<sup>39</sup> <http://www.unodc.org/unodc/en/frontpage/2013/February/conference-focuses-on-the-role-of-organized-crime-in-the-trafficking-of-fraudulent-medicines.html>

<sup>40</sup> <http://www.unodc.org/unodc/en/frontpage/2012/February/narcotics-control-board-warns-of-illegal-online-pharmacies-selling-drugs-to-youth.html>

<sup>41</sup> <http://www.wgig.org/docs/WGIGREPORT.pdf>

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UNODC and UNTOC relating to illicit online pharmacies and fraudulent cybercrime. The 2011 20<sup>th</sup> Session of UN Commission on Crime Prevention and Criminal Justice (CCPCJ) saw three resolutions adopted that reinforced global empowerment of UNODC to fight illicit online pharmacy activities: Resolution 20/4, “Promoting further cooperation in countering transnational organized crime.” Resolution 20/6, “Countering fraudulent medicines, in particular their trafficking” and Resolution 20/7, “Promotion of activities related to combatting cybercrime, including technical assistance and capacity-building.”<sup>42</sup>

This exploration has highlighted the different strategies employed to address the risks of illegal online pharmacies. There is a recognised lack of technical capacity, legal constraints and insufficient international enforcement cooperation. Also the authorities need to undertake more work with self-regulating, online drugs markets that promote harm reduction standards, to enhance their understanding of these criminal networks.

Despite the ‘risks’ associated with purchasing medicine online, many people actively engage in it. Having addressed the regulatory and policy approaches to this ‘problem’ the chapter now looks at criminological research that helps us understand why doing something that is forbidden might not be seen as deviant, and where it is seen as deviant, the activity continues.

### **3.3. Constructing Deviance**

For actions to be recognised as problematic and issues of concern in society, they need to have been constructed in such a manner. Early sociology and criminology used to be dominated by explanations for bad behaviour involving genetics or deprived environments. Such reasons often failed to generate reliable results and so the focus shifted to the structures that govern society, the agencies, regulators and lawmakers who establish the legal rules that define behaviours as crimes. In the next section I will draw on theories

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<sup>42</sup> [http://www.unodc.org/unodc/en/commissions/CCPCJ/session/20Reconvened\\_Session\\_2011/CCPCJ\\_20Reconvened.html](http://www.unodc.org/unodc/en/commissions/CCPCJ/session/20Reconvened_Session_2011/CCPCJ_20Reconvened.html)



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influential in the development of cultural criminology, as well as social theory perspectives, to conceptualise the conflicts of meaning in the feelings, emotions and reactions towards deviance. These ideas provide insight into how online medicine purchasing has been constructed, and how it could be perceived as deviance.

Becker's labelling theory fundamentally contend that no behaviour is inherently deviant or criminal, but is only perceived as such when others bestow the label upon the act. The labelling perspective (Plummer, 1979) has featured predominantly within criminology. Becker (1963) defined the labelling of deviance as the creation of social groups and not the feature of some act or behaviour. He claimed that deviance is simply rule-breaking behaviour that is labelled deviant by powerful persons or groups. Labelling theory has been used to examine subcultures, but shifts attention away from the rule-breaking act to the societal reaction to rule-breaking (Taylor, Walton and Young, 1973). It focuses on meanings and contends that the definition of an act as deviant depends on the way people react to it (Becker, 1963). Whether or not consumers, themselves, hold the view that online medicine purchasing is socially acceptable, is contrasted with how others might perceive the behaviour.

Extending Becker's assertions, Lemert (1967) challenged the notion that deviance leads to social control, instead claiming the reverse to be true – that in shaping what is understood to be deviant, social institutions are not controlling deviance, rather they are creating it. Lemert (1969) further posited that there are two stages to deviancy – primary and secondary deviance. Primary deviance is rule-breaking behaviour, whilst secondary deviance is behaviour that has been publicly labelled such and hence becomes central to identity. This leads to a 'master status', which overrides all other roles and sources of identity and is extremely difficult to disavow or shake off. An activity merely being acknowledged as detrimental is not enough to deduce that participation will equate to deviancy. It would appear that there are other processes and procedures involved that lead to the application and identification of this term. A deviant has to be defined as such and treated accordingly by others.

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Schur (1979, 1980) claimed that labelling behaviour deviant is a social process, and the outcome may be determined by personal attributes, real or imagined, rather than actual or presumed behaviour. Box (1983) described how the symbolic meanings attached to personal characteristics, along with the presumed relevance of abstract meanings associated with specific behaviours, are evident whenever an individual classifies their own actions or has them classified by others. *“It may be ‘who’ you are rather than ‘what’ you actually did that determines whether your behaviour is seen by others, and you as criminal”* (Box, 1983:169). The person’s position in society and the reaction to deviant behaviour, or the “attribution of deviantness to one’s behaviour” (Schur, 1979:197-271) are important factors to becoming deviant. This is not to say that this is a deterministic process. Just because an individual has been labelled a deviant does not necessarily mean that they will inevitably become more deviant or accept the label. It merely suggests that more deviance *“may occur, but does not have to”* (Matza, 1969:143-97).

This is a social constructionist conception of deviance, where the definition of deviance is constructed based on the interactions of individuals in society. Behaviours are not necessarily inherently deviant; however, they become so when the definition of deviance is applied to them. There are no inherently deviant acts as our understanding of the world is dependent on interactions between actors. However, if this approach were applied too strictly the implication would be that serious infractions that are not known about and/ or reacted to would not be considered as deviant. Hence in such circumstances an undiscovered killing would not be a deviant act, which is absurd. Alternatively an objective perspective presumes that there are general sets of norms of behaviour, rules, morals or conduct that are universally agreed upon (Rubington & Weinberg, 2007). Deviance occurs when moral codes or rules that are understood as such by everyone in society, are broken. Depending on the seriousness of the norm or law, rule-breakers become deviants, outsiders or criminals. However, the problem is that it is a fallacy to assume a shared acceptance (or disapproval) of different behaviours. Even sanctioned actions elicit contrasting reactions, for example in contemporary society pirating music or media online is an illegal offence, yet there are high levels of participation

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and little remorse about doing so (especially from the younger generation) (Bowker, 1999).

A critical perspective of deviancy has also been advanced (Jensen, 2007), which argues that societies understanding of deviance is fixed by those in power to maintain and increase their power. Adopting a Marxist perspective on crime and deviance, Chambliss (1975) talked about how the ruling class utilise the law to criminalise behaviours for their own protection. Criminal acts are widely distributed throughout the social classes in capitalist societies, but it is those in the subordinate class that get punished. It is in the enforcement of the law that the lower classes are subject to the effects of ruling class domination over the legal system, which impacts on the appearance of a concentration of criminal acts among the lower classes in the official records. The state becomes an instrument of the ruling class enforcing laws according to the realities of political power and economic conditions (Chambliss, 1975). Chambliss also contended that laws are often created for profit motives. This can be exemplified in the legislative and regulatory process behind the control and distribution of pharmaceuticals, where the owners and means of production (aka 'Big Pharma') are involved in lobbying for laws, which maintain or increase their profits. As has already been noted online counterfeit medicine trade negatively impacts the pharmaceutical industry and so the pharmaceutical corporations have vested interests to prevent medicine counterfeiting.

The response of authorities and pharmaceutical companies can be seen as a response to deviance by enforcing social control. However As Lemert (1951) has pointed out, by instituting social control deviance is created. Regulations designed to protect people from the 'harms' associated with online medicine ensure that transgressing them equates to deviancy.

This idea that social control leads to deviance can be seen in the Media's dramatic depictions of 'folk devils' (Cohen, 1972) who are labelled as deviant and have been ostracised by 'decent' society in response. Pearson (1983) noted that society has seen the deviant evolve from the street criminals of the 1600s and Victorian hooligans to Mods, Rockers, Skinheads, Hell's Angels, muggers, drug addicts and even protesting students. There are others

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engaging in behaviour outside of the norm, again not defined within law. These are members of society such as mental patients, sexual deviants, problem families and the long-term unemployed, who are sometimes frowned upon and less accepted. Such groups may receive the blame for some societal problems, and individuals who inhabit them are generally judged and looked down upon.

Of course there is another immeasurable group who indulge in behaviour that is unauthorised and morally unacceptable but are less visible. These individuals may be law-abiding and respectable citizens the majority of the time, but engage in some actions that can be considered to be wrong or deviant on occasion. Pearson (1983:4) refers to this category of persons as “*non-deviant’ deviants*” and gives examples of the following types of individuals: “*licence dodgers, after hours drinkers, parking offenders, drunken drivers, small-time tax fiddlers, men who take home ‘cabbage’ after work or, perhaps, their barbiturate dependant wives*”.

After the rise to dominance of neo-liberal criminology in the guise of Rational Choice Theory (Cornish & Clarke, 1987; Stenson and Sullivan, 2001), and the Left realist response (Lea & Young, 1984), Deviancy theory, underpinned by Marxism, had fallen out of fashion. The one-time central figure, Jock Young, had shifted his position and begun criticising his previously strongly-held views, coining the term Left Idealism in an openly provocative move (Downes & Rock, 2011). Criminology was now, for many, an openly political discipline (Stenson & Cowell, 1991). But after the fall of the Conservatives and the rise of New Labour came the global recession that problematized the neo-liberal laissez faire approach to the economy. The financial crash reignited the nascent socialism in some academics, not least Jock Young. With Jack Katz’s *Seductions of Crime* (1988) as a foundation, Cultural Criminology soon developed, and Young was once again central to these developments. It is arguable whether or not Cultural Criminology, like Labelling, can be called a theory at all (Webber, 2007). However, the initial foundation provided by Katz were soon developed and worked on, not least by Young (Young, 2003). Katz argued that the background structural causes of crime were of limited use, and

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the 'foreground' emotional meanings more important. Young and Mike Presdee (*Carnival of Crime*, 2001) began injecting ideas that they had developed, and Young had neglected in the 1980s and 1990s, back into the Cultural Criminology script in the first decade of the millennium.

Negotiating the age old tension between structure and agency, cultural criminology began to consider how individuals and groups create cultural meanings and their own cultural perspectives in a society comprised of morals and rules which is not of their making (Ferrell et al. 2008; Young, 2003). Motivations for rule breaking are more than individual reasons; they encompass cultural products such as shared accounts and accomplishments. Presser and Sandberg (2015) claim that people operate as narrative creators, continually writing and rewriting their stories in relation to the multitude of options around them. The individual self is an exclusive pattern of constructed meanings (Presser & Sandberg, 2015).

Cultural criminology widens the narrow notions of crime and deviance present in legal and media discourse to include symbolic presentations of transgression and control (Ferrell et al, 2008). According to cultural criminologists culture is comprised of collective meaning and identity, hence "*the government claims authority, the consumer considers advertised products - and 'the criminal,' as both person and perceived societal problem, comes alive*" (Ferrell et al, 2008:3). Furthermore, culture implies a shared public performance, involving a process of public negotiation (Ferrell et al. 2008). In undertaking the 'risks' involved with purchasing medicine online, individuals are clearly and unambiguously both deviants and victims contributing to Beck's 'risk society' where the hazards created by modernisation, are responded to.

The challenges to healthcare expertise can be understood as a result of the emergence of the risk society (Beck, 1992). A key defining feature of modern society is that the relationship between the individual and society has shifted due to the increase in technology, consumerism and globalisation (Beck, 1992; Giddens, 1990). This has led to a concern about dangerousness and risk becoming the main focus for governments in accordance with individual's personal decision making (Mythen, 2004). Giddens (1990) notes that due to technological advancements in contemporary society individuals can both

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produce and diminish risk. The contradiction is that individuals are increasingly regulated whilst also encouraged to pursue personal freedoms. As such there is a growing sense of mistrust between the public and experts.

There have been debates about the tension existing between public policies and private programmes established to address crime, deviance, and public safety (Mitchell, 2001; Mudge, 2008). This conflict involves the relinquishment of public well-being out of the public realm (i.e. the government) to a private and potentially private profit motivated industry. This shift is known as neoliberalism and is associated with the earlier discussions on individual responsibility and challenges to healthcare expertise. Neoliberalism is a political, economic, and social ideology that advances a free market philosophy and an emphasis on deregulation (Frericks et al., 2009). Free markets place priority on profit motive, privatisation and deregulation also does not always ensure that individual well-being is met, as basic human needs can suffer under these regimes. Dependence on neoliberal philosophy and free market economy means that things are conducted via cost benefit analyses. The responsibility of the state is relinquished to private companies; this reduces state accountability to care for its citizens (Mitchell, 2001).

Whilst public programmes concentrate on the social control of deviance via punishment, private programmes focus on prevention. The latter may focus on groups or individuals who are presumed to be more 'at risk' of engaging in deviant behaviour. Often, the reaction towards deviant behaviour has been one of stigmatisation and criminalisation, and the harsh punishment of such behaviours (Liazos, 1972), where the public route has been adopted. However, the action of purchasing medicine online has not been criminalised or socially sanctioned, though it has been deemed a 'risky' behaviour.

Changing social conditions mean that the public can challenge expert forms of knowledge, and this may be viewed as a problem. Nowadays expertise is not limited to position and status as people access the same knowledge and information, previously only available to the elite. The development of mass information tools, such as computers, mobile phones and the Web, mean that knowledge and expertise are no longer limited to the privileged that have

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undergone specialist training. In a world where individuals increasingly need to manage risk and problem solve in their everyday lives, such knowledge and expertise is crucial (Giddens, 1990). Hence there is a tension between experts and citizens. For example people might question why they need regulatory bodies to make healthcare decisions for them.

Crime is real and has existed for a long time, but it is also socially constructed through hysteria and the notion that it is always new and unique and never happened before. However, compared to some of the earlier depictions of the 'deviant' individuals engaging in deviant online behaviour such as the purchasing of medicines are not the types of deviants that instigate fear in others. The purchasing behaviour is a component of a wider lifestyle choice that appears not to cause concern or impact on others in society. Nevertheless, it has been identified as problematic by the authorities, as noted earlier in this chapter.

Having explored how actions come to be viewed as unauthorised and deviant, the chapter now turns to how people respond to being labelled deviant, by justifying the very behaviour that attracted said label in the first place.

### **3.4. Justifying Deviance**

Why do people engage in deviant behaviour even though they know it to be wrong, or at least could be perceived as wrong by others? Sykes and Matza's (1957) theory of techniques of neutralization, offers an explanation as to why people sometimes violate societal norms and laws. Sykes and Matza challenged claims that there was a distinctive subculture amongst offenders and delinquents. Instead, they asserted that most delinquents are essentially in agreement with larger society and know that delinquent behaviour is wrong, and that they share conventional beliefs about conduct. Sykes and Matza supported this contention by pointing out that if a delinquent subculture were to exist then we would expect the delinquent to view their illegal behaviour as morally correct and to display no feelings of guilt or shame upon exposure. Yet the evidence indicates that many delinquents do experience "*a sense of guilt or shame*" (Sykes and Matza, 1957:664-5). This confirms that offenders identify

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with the dominant norms regarding right and wrong behaviour, and encounter negative emotions when confronted with their rule-breaking actions.

If the deviant shares the same value commitments as the non-deviant, then how are we to understand the processes that enable someone to engage in “criminal” behaviour? Sykes and Matza’s solution to understanding this quandary appears in the form of their techniques of neutralization, which they define as “*extensions of defences to crimes, in the form of justifications for deviance that are seen as valid by the delinquent but not by the legal system of society at large*” (1957:666). Influenced by existential thought and what Sartre (2003:72) refers to as “*bad faith*” (*mauvaise foi*), the techniques of neutralisation echo a form of self-deception in which we lie to ourselves in order to evade moral responsibility for our actions. This notion of metaphorically ‘burying our heads in the sand’ and turning a ‘blind eye’ to elements of our behaviour because they might have negative repercussions, was further explored by Cohen (2001) in his work ‘*States of denial.*’ Cohen (2001) considered how it is possible that people are both knowing and unknowing at the same time, where the mind unconsciously (or consciously) keeps troublesome information away. Everyday denials are conducted to ensure that uncomfortable truths are expelled from the forefront of our knowledge, however, we are aware of them in the back of our minds. When faced with the suppressed realities the self-deception is interrupted and further denials are turned to in the form of techniques of neutralisations.

The techniques of neutralisation equate to rationalisations that offenders use to convince themselves that it is admissible to transcend dominant norms of conduct, thereby allowing them to deviate and justify that deviation. The use of these techniques also serves as an emotional functionality as they help mitigate the feelings of remorse, guilt and shame that would otherwise be experienced in the aftermath of criminal or deviant behaviour. Although the legal, moral, and ethical issues are not entirely rejected, individuals are able to temporarily absolve themselves from these codes. The neutralization process means that deviant behaviour can be engaged in without assuming a permanent criminal identity, because the opinions of the dominant society



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have been sufficiently neutralized. The usual social controls that restrict deviant and criminal behaviour are inefficient, allowing individuals the ability to contravene societal conventions (Sykes and Matza, 1957).

Sykes and Matza's (1957) techniques of neutralization comprise various denials and appeals. Denial of responsibility involves the offender denying that the wrongdoing was their fault and blames instead an external factor such as alcohol or drugs. Denial of victim sees the offender claiming the victim was in the wrong, for example in a rape case where the offender claims that the victim led them on. Denial of injury involves the offender claiming that the victim was not really hurt by the crime; this could be used to justify theft from companies as opposed to the individual in that they can afford it. Appealing to higher loyalties is also a way of justifying deviant behaviour, for example if the rule of law had to be ignored due to the fact that more important issues were at stake such as standing up for race/religion/political beliefs etc. In addition, the offender may feel a sense of unfairness in being singled out and punished for an action that they feel is not unique from what others have done. The individual turns accusations of wrongdoing back upon those who have condemned them for their behaviour. Criticism might be expressed of those who pass judgment, therefore condemning the condemners; for example the government might be viewed as corrupt.

Matza and Sykes (1961) also explored why rule-breaking and risky activity can be appealing in their article '*Juvenile delinquency and subterranean values.*' The simple answer purported by Matza and Sykes is fun, the search for excitement, thrills and kicks drives transgressions. The fact that an activity is breaking the law is what makes it exciting (Matza & Sykes, 1961). Although the focus is again on delinquent youths, the concept is transferrable because it highlights a cultural perspective, one that sometimes celebrates daring and adventure. Rule-breaking behaviour is not always abhorred, it can be commodified, consumed and celebrated (Ferrell et al. 2008).

These ideas explained how juveniles could shift from being law-abiding to criminal and then back to law-abiding again in a process of 'drift' (Matza, 1964). This was further developed where the deterministic notion of the 'constrained delinquent' who is fundamentally distinct from law-abiding

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citizens was rejected. Matza claimed that the drift into delinquency may occur from either inner or outer compulsion along with underlying influences. Matza indicates a firm difference between mundane drifters who do not become criminals in adulthood and those who do, due to processes such as compulsion or constraints for example. Taylor, Walton and Young criticized this distinction for ignoring the “*full implications of his sociology of motivation*” (1973:140) suggesting a major contradiction in Matza’s critique of determinism.

A cultural response towards threats concerning social status involves the process of ‘othering’. Weis (1995:17) argues that othering not only “*serves to mark and name those thought to be different from oneself*” but is also a process through which people construct their own identities in reference to others. Providing a means to justify privilege, the normal are distinguished from the deviant, and the law-abiding distinct from the criminal. Ferrell et al. (2008) claim that othering is a means of highlighting a lack of culture. ‘Others’ have failed to share the values needed to assimilate into the moral order, hence acquiring the status of deviant. These deviants cause problems for the rest of society who are moral and virtuous. Othering, in the context of healthcare, has also been discussed by Johnson et al. (2004), in their study of the interactions between healthcare providers and South Asian immigrant women, where social and institutional contexts created conditions for othering behaviour.

Cultural criminology argues that such psychodynamics are not a result of an individual’s past experiences, but are instead determined by current social problems and stresses arising from the existing social structure (Ferrell et al. 2008). Hence an appreciation of the present situation and current social issues is necessary to understand othering and how deviancy comes to be recognised as such.

Deviance can be justified as a way to seek control over one’s life. Lyng (1990) and Ferrell (2005) have undertaken edgework studies investigating individuals who voluntarily engage in extreme acts of risk-taking such as sky-diving, illegal graffiti writing and illicit motorbike racing. These studies have found that

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participants are not dangerously out of control or self-destructive, instead they are pushing themselves to the edge. They squander control to regain control (Ferrell et al. 2008). Such risky acts are a means of reclaiming control over one's life, retaliation against the structures that deprive individuals of their autonomy (Lyng, 1990). Edgework allows people to develop the very sorts of skills that authorities seek to control.

Cultural criminology acknowledges the externalisation of excitement associated with resistance. Influenced by Katz's (1998) work, which highlighted that crime is about presence and 'sneaky thrills,' cultural criminology moves beyond the objective perspective to consider the subjective view of the criminal. Many deviant activities that appear to be about risk-taking actually represent an attempt to exercise control and take personal responsibility. In a society where people are increasingly controlled, rule-breaking/ deviancy offers excitement and the opportunity to regain control (Jewkes, 2010). The Web enables individuals to bypass regulatory controls and challenge authoritative restraint, especially in relation to healthcare choices and purchasing medicine. This can also be viewed as an act of self-expression.

Deviance can also be viewed as an expressive act; Presdee (2003) claims that everyday life is filled with drama and emotional intensities that impact upon even the most mundane of routines. Social life is suffused with emotive extremes from the phenomenology of everyday lived experiences to the *phenomenology of crime* (Katz, 1988). These ideas merge with those of Goffman's 'Presentation of Self', which will be discussed in more detail later in this chapter.

In contemporary society the search for excitement and the tension of conformity are more intense and ambiguous (Ferrell et al. 2008). This emphasis on expression is antithetical to rational choice theory (Cornish & Clarke, 1987), which dominated orthodox criminology. Embodying an uncomplicated rational/ instrumental discourse, rational choice theory maintains that crime occurs where opportunities are available and individuals have low levels of social-control, especially where people are impulsive and focused on the short-term (Felson, 1998). Existential motivations are neglected, and individuals are presented as calculating, deliberate actors,

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taking advantage of criminal opportunities where possible. In this sense criminality can be understood as behaviour similar to consumerist decision making, with cost-benefit economics affecting choices. However, this approach overlooks the lived experience, the meanings attributed to transgression that provides insight into the emotional perceptions of individuals. The previous chapters have addressed the challenges to authority that are involved in the purchasing of medicine online, and the excessive commodification of consumer culture, these issues along with potentially engaging in behaviour that is deemed to be risky, highlight that expression is significant in deviancy.

Jack Katz's (1998) *Seductions of Crime* helped to establish a phenomenological focus, where the complexities of social interaction, emotions, consciousness and situation are central to understanding crime and deviancy. Focusing on the foreground experiences of people, rather than the background factors such as class or ethnicity, Katz claims that emotions are ambiguous. On the one hand we are unable to control our emotions, such as when we feel guilty or ashamed, or find something funny; on the other hand emotions are a subjective part of our lives and we are able to own our reactions, such as providing an expected response to certain situations for example sympathy towards someone who has received bad news. Therefore Katz in his later work 'How Emotions Work' (1999: 1-2) questioned:

*"when shame or rage flood through experience, where is the source of inundation, where are the gates that let the rush of feelings come through, if they are not within. If we idiosyncratically own our emotions, why can't we fully own up to them?"*

Katz suggested three answers to these questions. The first considered emotions as 'situationally-responsive' and 'situationally transcendent' narrative projects. Here, the individual attempts to make sense of what is socially visible in both the immediate situation and the aftermath. The second, Katz described as 'interactional processes', which explore how people shape their emotional conduct in response to the readings and reactions given to their emotions by

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others. Lastly, 'sensual metaphors' refer to the framework of actions changing as people move in and out of their emotional states such as shame anger and rage. Katz's ideas accentuate the earlier symbolic interactionist work and Matza's state of drift.

Much of this discussion of deviance is about identity management as actors shift, or drift, between different moral and legal positions. Having considered how deviance is constructed and how those labelled in turn justify the deviance, I now consider how and why deviance is managed. I draw on Goffman's conceptual contributions concerning dramaturgy, the presentation of self and stigma, in order to underpin further the concept of respectable deviance.

### **3.5. Managing Deviance**

Despite originating in an era that predated many of the digital communication technologies that have become important to social interaction, Goffman's theories of human behaviour and interaction help to explain, understand and grasp social life on the Web. His work is often located in symbolic interactionism, although he may well not have considered his work to be aligned with this approach.<sup>43</sup> Goffman discussed mundane and everyday social activities and interactions such as walking along the street and getting in a lift; he was especially interested in understanding behaviour that occurred in public places. He became concerned with 'regulation', that is, the way people handle or manage themselves in face-to-face interactions with others; he studied this partly through his exposition of the concept of dramaturgy. He suggested that social interactions are like a play or dramatic performance within which individuals perform different selves through multiple performances (Goffman,

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<sup>43</sup> Notwithstanding Goffman's own inadmission, Thomas J. Scheff, a student of Goffman, claims that for the majority of his career, Goffman was a symbolic interactionist, specifically in the tradition of Cooley. Scheff asserts that up until 1974 (and Goffman's work on frame analysis), the only sustained theoretical structure in Goffman's work followed Cooley's supposition of the looking-glass self. As Cooley assumed shared awareness in interactions, with pride or shame being the resulting emotions, Goffman also placed such importance on common comprehension with positive or negative states of consequence. However, Goffman accentuated embarrassment over shame and also discussed the management of embarrassment or shame (Goffman, 1959). Conceptual definitions of emotions are central to Cooley's conjecture.

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1959). The presence of others – the audience - allows individuals to adjust and perfect their behaviour, a technique Goffman termed ‘impression management’. He was especially interested in the way different types of setting shape impression management or performances. He delineated ‘front’ and ‘back’ stage regions for interaction performances. The ‘front stage’ is a place where the performance is public and seen by many, and ‘backstage’ is where access is more controlled and limited (1959:113). Goffman also used ‘dramaturgy’ to introduce scripts, which set out patterns that structure talk and interaction despite the appearance of improvisation. These ideas about staging have proved especially useful for thinking about healthcare, for example in understanding public and visible areas such as waiting rooms and clinics, and less accessible areas such as operating theatres (Fox, 1997; Pope, 2002).

Goffman’s ideas about stigma are perhaps the best known of his contributions, having become part of common sense language. He defined stigma as “*the situation of the individual who is disqualified from full social acceptance*” (Goffman, 1963:9). This might be because of a visible stigma such as a scar or functional disability, or because the individual has failed to conform to socially prescribed norms. Goffman examined how stigmatised persons struggled to reconcile gaps between their own perceived reality and the identity expected by the social group, and used performance to deal with this. Examples of the use of his ideas regarding stigma include Leary et al. (1994). They discussed the role of self-presentational motives in health-relevant behaviours, surmising that several patterns of behaviour that increase the risk of illness and injury arise from people's concerns about the way they are regarded by others. In some cases that they studied, such as sun-induced skin cancer and eating disorders, self-presentation may be the most important factor placing the person at risk. Yet in other instances, for example contracting HIV through unsafe sex or using steroids, self-presentation is but one of many factors leading to unhealthy behaviours. Similarly, Culos-Reed et al. (2002), in their study of cosmetic surgery, argued that there are significant differences between the self-presentational concern and public self-consciousness of those

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who have surgery for appearance motives and those who elect to have treatment for health-based motives.

In purchasing medicine online, there may be a social stigma in engaging in unauthorised behaviour. This is especially prevalent where people are aware of the risks and how other people could react to the behaviour. One way of overcoming the deviant label is to manage identity. Goffman contended that people controlled information about stigmatising attributes. Among Goffman's key insights was that stigma is the result of demands for normalcy. We are shown the ideal way to look, behave and comprehend ourselves. Goffman showed that stigma involves not so much a set of concrete individuals who can be separated into two groups (the stigmatised and the normal) but a pervasive two-role social interaction process. The normal and the stigmatised are not persons, but rather perspectives (1963:163-4). Goffman used these ideas to suggest that if people are to refer to the stigmatised individual as deviant, it might be more suitable to regard them as a 'normal deviant' (1963:155).

Presentation of self is therefore carefully managed to avoid the stigma associated with being labelled deviant. If behaviour has been framed as problematic then those engaged in such activities are less respectable, than their conforming counterparts. Taking into consideration the earlier discussions regarding how deviance is constructed and justified, managing presentation is intrinsic to appearing respectable, despite being associated with behaviour that others may view as deviant.

Respectability involves adhering to societal expectations and being a good citizen. Individuals should follow the rules and not challenge authority in order to be respectable. The Web allows individuals to do both. Ordinarily obtaining medicines away from regulatory controls would be dealt with punitively, however the Web allows people to circumnavigate medicine legislation without sanctions for the purchaser. Although the media and governmental campaigns go some way to label online medicine purchasing, they are not able to criminalise purchasers. This is a key distinction between perceptions towards crime and deviance. Hence there is a contemporary cultural shift whereby people are both respectable and deviant at once.

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Even though the deviant label is attached to the purchase and consumption of illegal drugs, it does not stop people from engaging in such behaviour, even for individuals who are generally law abiding in other areas of their lives (Parker et al. 2002). Karstedt and Farrall, in 'The Everyday Crimes of the Middle-Classes' (2007), explored illicit practices committed by individuals who think of themselves as 'respectable citizens' and dismiss the 'criminal' label. Using a sample of the population aged 25-65 in England and Wales, and a cross-comparison with Germany, Karstedt and Farrall's study explored 'everyday crimes' that do not carry the 'anti-social' status. The results were based on survey data conducted in 2002 with 1,807 respondents. They found that 61% of respondents had committed at least one of the following 'offences': not paying TV licence fees; false insurance claims; claiming non-entitled refunds; tax avoidance; and false benefit claims against business, government or employers. Not all of these behaviours are illegal; however, Karstedt and Farrall claim they are morally dubious and potentially deviant, and are 'everyday crimes' in the sense that they are part of many people's experiences. They argue that immoral behaviour appears to be normal practice, but is typically justified as exceptional 'one-offs'. People participating in illicit or dubious behaviour, when they find themselves on the receiving end of others engaging in similar activities, appear quick to condemn. Karstedt and Farrall's work relates to offline settings, and these ideas have not been applied to the Web.

Although some of the theories that have been discussed thus far in this chapter were developed prior to the focus on crime and deviancy online, some have been applied and tested in relation to various cybercrimes. The next section considers some of the studies that have conducted work on the web using criminological theories on deviance and social control. Furthermore, there will be a brief consideration of the studies that have applied Goffman's ideas to online behaviour.



### **3.6. 'Online' Deviance**

Wall (2007) has discussed how the Web has created new opportunities for criminal activity. The Internet society (Castells, 2001) has transformed criminal behaviour, enabling new conduits for criminal action. Castells claimed that the information age has altered relationships of power, production and consumption (2001). The Internet has increased change and emphasised the idiosyncrasies of late modernity, specifically the “discontinuities” highlighted by Giddens (1990) that isolate modern and traditional social orders. Jaishankar (2009) suggests that as the Web cuts across a wide spectrum of society, theoretically anyone can become a criminal.

However, Jewkes (2003, 2007) and Yar (2006) have stated that one of the most perplexing aspects of contemporary empirical criminology is that it has been slow to engage with online crime. Recent work (Thomas and Martin, 2006; Franklin et al., 2007; Holt and Lampke, 2010; Yip et al., 2013) has focused on crimes such as hacking, intellectual property and fraud, but other more mundane and everyday online activities have been overlooked. In the following discussion I show how studies utilising criminological theories on deviance and social control concentrate on the actions most commonly associated with cybercrimes.

In a study on hackers, Turgeman-Goldschmidt (2005) investigated the meaning that hackers attribute to being labelled as a hacker. In-depth interviews were conducted with 50 self-identified hackers based in Israel. Recognising the evolution of the term hacker (from skilled computer geniuses to criminals who use computer related technologies in the commission of their crimes), Turgeman-Goldschmidt noted that some individuals who participate in certain computer-related activities may acquire the label of hacker, start to acknowledge it and view themselves as different to mainstream computer users. However, instead of the label having pejorative connotations and affecting other aspects of life, the study found that being recognised as a hacker had little impact on successful mainstream achievements such as obtaining prosperous employment. Upon examining the ‘master status’ (Lemert, 1969) of hackers, Turgeman-Goldschmidt (2005) found that the status of ‘computer expert’ rather than ‘computer deviant’ was preferable by the

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hackers. This suggests that hackers do not suffer with lowered opinions about themselves or their self-identity; rather they actively seek out the label of 'hacker' because it makes them feel more proficient. However, the findings from this study could be questioned due to the participants being self-defined hackers, as such the suggestion is that there is a positive attitude towards the label from the outset. It might have been useful to interview people who could be considered part of the hacking community but don't self-identify as such in order to obtain a more rounded perspective towards the label.

An area of cybercrime that has received criminological attention is that of digital piracy. This concerns the illegal distribution of copyrighted music, films, and software files, whether for profit use or personal motives. Sykes and Matza's (1957) techniques of neutralization has been used to study digital piracy and file sharing in Moore and McMullan's (2009) study. Using university students for their sample group of interviews, Moore and McMullan found that individuals who engaged in file sharing actions, expressed techniques of denial of injury and denial of victim to justify their behaviour. The commonly held opinion was that downloading music and films, and sharing music and film files was not harmful to the artists involved as they would still get incomes from the record or film companies and/ or concerts. However, the sole attention on university students limits the study as file sharing behaviours extend beyond such populations, and are widespread socially and conducted on a regular basis by otherwise 'law abiding' citizens (Yar, 2013). Nowadays the software to become a file sharer is easy to obtain and master and so anyone with access to a computer and the Web can theoretically become a digital pirate. Having different perspectives from different groups of people could be interesting to see whether the same beliefs are held, and if there are any distinctions in the justifications they provide for their actions.

Whilst Moore and McMullan's (2009) study was qualitative, Hinduja's (2007) study on digital piracy also using techniques of neutralization followed a quantitative approach. Focusing on attitudes towards file sharing in relation to software piracy, Hinduja's study surveyed 507 university students. The study found that techniques of neutralisation were tenuously associated with file

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sharing as many of the respondents did not appear to view software piracy as a moral issue.

Digital music piracy was investigated by Higgins et al. (2008), who conducted a survey with 200 students about the file sharing of music files. Higgins et al. (2008) found that digital piracy was linked with techniques of neutralization. Individuals in the study indicated that they take a 'holiday' from social control using neutralization techniques to allow them to pirate music without developing a criminal identity. As with Moore and McMullan's study, Hinduja's and Higgins et al.'s findings are constrained by the focus on a select type of sample group. They are also hindered by the usual limitations associated with survey methods, in that explanations for attitudes cannot be investigated and explained in depth. Higgins et al.'s study also used a comparatively short longitudinal study so trends over time could not be established, for example whether the techniques of neutralization changed in relation to age and experiences. Nevertheless, all the studies evidence how techniques of neutralisation can be used to understand online deviant behaviours and shifts into behaviour that is technically illegal.

In 'Cybercrime and the culture of fear', Wall (2007) addresses the conceptual origins of cybercrime and the way online insecurity and risk are symbolised and widely used to describe the crimes and harms that are committed using networked technologies. This term may be extended to include the harm to which the consumer allows himself or herself to be vulnerable via the purchasing of medicine, especially prescription medicine, online. There are also obvious links to the seller's perspective, if they are intentionally aiming to sell fraudulent goods such as counterfeit or substandard medicines.

This potentially leads us to new forms of crime and deviance that are less traceable. Criminal behaviour may have altered due to the assumption that behaviour online is anonymous and cannot be tracked. However, while it is true that individuals can use false identities online – as they can also do offline – an often-neglected characteristic of networked technologies is that every move online can be tracked by a data trail left behind (Wall, 2008). In Presdee's view, the Web has become a 'safe site' for people's second life (Presdee, 2000:54). It provides an environment *"where we can enjoy in private immoral acts and*

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*emotions*” (Presdee, 2000:64). Presdee also refers to the consumption of crime as a “*blissful state of non-responsibility*”, a sort of never-ending “*moral holiday*” especially on the Web. This is perhaps true of the early days of the Web, but in the post-Snowden<sup>44</sup> world, a more cynical outlook might be taken of the ‘blissful state of non-responsibility.’

Wall (2005:94) suggests that we have been looking at a new phenomenon through the wrong lens. He highlights the “*transformative impacts*” of the Web on deviant behaviour to envisage the behaviour that would remain were the Web to disappear, thus demonstrating how the Web is “*a conduit for criminal activity*”. However, he also discusses how it enables the governance of behaviour and allows policing agencies to police cybercrimes (Wall, 2005).

This discussion has demonstrated how criminological theories have been useful to understand online emerging deviant behaviours. However, the focus on specific ‘cybercrimes’ such as hacking and piracy overlooks the realities of everyday online behaviours that transgress rules and norms, but which are not necessarily criminalised by law.

### **3.7. Applying Goffman’s ideas to digital lives**

In his later writing, Goffman looked at advertising and interactions where parties were not co-present; however, his work predominantly explored face-to-face interactions. All of his writing predated the emergence of many now commonplace digital forms of communication and interaction – including email and the Web. However, Knorr-Cetina (2009) has argued that Goffman’s work can be useful for understanding digitally mediated interactions. She has used his ideas to explore “*synthetic situations*” such as digitised stock market trading, where buying and selling shares takes place in virtual space such that “*the interacting parties meet in time rather than in a place*” (Knorr-Cetina, 2009:79).

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<sup>44</sup>Edward Snowden leaked classified information from the United States National Security Agency (NSA) in 2013, which revealed many global surveillance programmes <http://www.theguardian.com/us-news/the-nsa-files>

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Goffman's ideas have also been applied to mobile phone communication. Rettie's study (2009) used his ideas about presentation and etiquette to understand the technology behind SMS (text) and email messaging, showing that like face-to-face interactions, these are governed by normative expectations. This work has much in common with Spitzberg's (2006) examination of computer mediated communication, which drew heavily on the dramaturgical perspective offered by Ring and colleagues (Ring, Braginsky and Braginsky, 1966; Ring, Braginsky, Levine and Braginsky, 1967; Ring and Wallston, 1968) to understand performances and scripts in this digital space. Elsewhere, Adkins and Nasarczyk (2009) examined asynchronous interactions on the photo-sharing website Flickr, synthesising the theoretical and methodological insights of Goffman (1959), Garfinkel (2002) and Sacks (1995) to show how a social order was created around the practices of sharing photographs online. Most recently, Murthy (2012) has used Goffman's ideas to think critically about the microblogging platform Twitter,

This brief review of existing research applying Goffman to digital interactions shows that his ideas continue to resonate. However, much of his influential work appears to have been overlooked in the context of understanding online interactions related to managing deviance.

### **3.8. Summary**

The purchase of medicine from the Web can be illegitimate or illegal, and it has been constructed as risky and problematic in relation to counterfeit medicine, criminal activity, and health risks. The Web, in allowing has been blamed for counterfeit medicine infiltrating developed countries. The risks associated with criminality focus more on the illegal drug trade and the vendors of illicit substances than on prescription medicine misuse, adverse side effects and health risks associated with purchasing medicine online. Policy and authority responses to the issue have been inconsistent and many of the strategies employed thus far have proved ineffective and/or have not actually protected consumers.

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This chapter has explored theories of deviance that can help to understand the impact of online medicine and how consumers respond to being labelled deviant. Online medicine purchasing can be positioned as rule breaking and deviance. It is also framed as problematic and risky creating a perception that control is needed. Interestingly however, the demonisation that generally accompanies the label of deviancy has not applied to online medicine purchasing as it has with illegal drug use and other activities, instead this new behaviour falls into a grey area that appears to challenge authority and expertise yet is not subject to social ostracising. I have described how critical criminology has considered how people justify their deviant behaviour using techniques of neutralization, and using the ideas of Erving Goffman - how people manage their behaviour and presentation of self, to offset potential stigma.

One way of understanding the phenomena of online medicine purchasing is by using the concept of respectable deviance. This can therefore be understood in three stages: firstly, that a particular behaviour (in this case online medicine purchasing, where it involves accentuated levels of illegitimacy) has been constructed as deviance, secondly, people are compelled to provide justifications for engaging in such behaviour (even if they themselves do not consider it deviant), and thirdly that presentation of self is carefully managed in order to maintain respectability. This provides the foundation for the fifth research question *5. How do people engaged in online medicine purchasing view their conduct once aware of it being constructed as risky and problematic by external agents?* and objective 5. *Apply a theoretical framework for analysis.*

In the next chapter I will describe how I designed a study in order to look at the new 'consumers' of medicine online.

## 4. Methodology

This chapter outlines the methodology and the methods employed in this research. As this research is concerned with the Web, online methods were seen as appropriate for gathering data. Though Web research has grown over the past decade, new methodologies are still emerging. Traditional observational methods have been adapted to study the virtual environment, and qualitative and quantitative methods have been used to describe Web activity.

A mixed methods approach integrates quantitative and qualitative research within a single project (Bryman, 2004:452), and Green and Thorogood (2004:207) suggest that using different methodological approaches enriches the research process toward a richer understanding. I needed to choose the most appropriate data collection techniques to study the online purchasing of medicine. A mixed methods approach involving three sequential phases – observation of online forums, an online survey and semi-structured interviews – was adopted. This research was inductive; a broad theoretical criminological perspective on deviance and the research questions identified informed the work. Through the systematic collection of data and rigorous analyses the broad theoretical perspective was honed into a more specific theory – respectable deviance, which informed and underpinned the overall findings.

The research was guided by an interpretive paradigm, influenced by social constructionism. An interpretive paradigm supports the idea that there are many truths and multiple realities, and focuses on the holistic perspective of the person and environment (Weaver and Olson, 2006). In addition, it is associated more with methods that provide an opportunity for the voice, concerns and practices of research participants to be heard (Cole, 2006). Cole further contends that qualitative researchers are

*“more concerned about uncovering knowledge about how people feel and think in the circumstances in which they find themselves, than making judgements about whether those thoughts and feelings are valid”*  
(2006:26).

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Focusing on human interest and meanings, research projects guided by an interpretative approach are less concerned with representative populations (Wall & Williams in Davies et al. 2011). Although the methods in this research often relied on convenience sampling (due to the nature of the Web itself), generalising the data was less important than participant's viewpoints in relation to online medicine purchasing.

Taking a critical perspective towards the 'problematic' framing of online medicine as risky by external agents (as per the policy and authority positions outlined in the previous chapter discussions and the consideration of deviancy literature), my methodological approach was informed by both social constructionism and symbolic interactionism. In exploring online medicine purchasing I am aware that I invariably drew attention to the risks, however, participants demonstrated 'knowing and not-knowing' (Cohen, 2001) about these and the inquiry then rendered the issue open. This research sought to combine different research methods that would capture subjective views and experiences as well as documenting and describing patterns of behaviour in relation to online medicine purchasing and the associated risk hegemony. This led me to consider using an ethnographic approach, which can combine a number of different methods to explore social phenomena.

The traditional practice of ethnographic<sup>45</sup> field study has been extended to research about Web communities and cultures, and is often called virtual ethnography (Hine, 2000) or netnography (Kozinets, 2002). Virtual ethnography shifts the ethnographic tradition of the researcher as an embodied research instrument to the social spaces of the Web (Hine, 2000). Widely used in consumer research online, netnography is a newer term used to describe a qualitative, interpretative research methodology (Kozinets, 2002) that adapts the traditional, in-person ethnographic or anthropological method to observation of online communities and cultures formed via computer-mediated communications. Netnography distinguishes four main aspects of virtual interaction that are independent from their real-world counterparts

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<sup>1</sup> One of the most frequently cited definitions of ethnography is by Hammersley and Atkinson (1995, p.1): '*... we shall interpret the term 'ethnography' in a liberal way, not worrying much about what does or does not count as examples of it. We see the term as referring primarily to a particular method or sets of methods. In its most characteristic form it involves the ethnographer participating, overtly or covertly, in people's lives for an extended period of time, watching what happens, listening to what is said, asking questions—in fact, collecting whatever data are available to throw light on the issues that are the focus of the research.*'



(Kozinets, 2002). First is the textual context of the online environment. Second is an unprecedented new level of access to the previously unobservable behaviours of particular interacting groups of people. Third, though traditional interactions are ephemeral as they occur, online social interactions are generally saved and archived, creating permanent records. Fourth, it is unclear whether Web spaces are private or public, or some unique hybrid of the two. These features provide opportunities and challenges for doing ethnographic research online.

Some commentators argue that observational research that involves no direct participant interaction is not meaningful (Clifford, 1997). It has been suggested that online ethnographies should provide a Geertzian sense of 'thick description' (Geertz, 1973) through the immersion of the researcher in the life of the online culture or community (Hine, 2000; Markham, 1998). One possibility is for the researcher to fully participate as a member of an online community. This is more faithful to the traditional ethnography and is distinct from other online methods of data collection such as data mining and social network analysis, which may simply harvest data about activity online.

One important feature of online settings is that they provide the opportunity for unobtrusive, covert observation sometimes termed "lurking". Hine (2000:25) refers to lurking as a "*known presence but no observable trace*". Lurking is a known phenomenon on the Web, where people read but do not post in online communities. Evidence of lurking can be found through access records, but such lurking seldom leaves a trace researchers can analyse. Virtual ethnography can exploit this aspect of the Web. We can lurk unseen online for a time, but this method of research entails a degree of deception, which raises ethical issues. Some researchers argue that covert research is necessary because announcing one's presence as an online researcher (Clark, 2004; Roberts, Smith and Pollock, 2004; Sveningsson, 2004) may disrupt 'natural behaviour' (Soukup, 1999).

Some authors claim that observational studies of online cultures are a form of ethnographic research (Mann and Sutton, 1998; Cooper and Harrison, 2001; Holt and Lampke, 2010; Durkin and Bryant, 1999). Although I employed a netnographic approach in the first phase of the study I feel that I was not immersed in the online communities or able to have a sustained presence to

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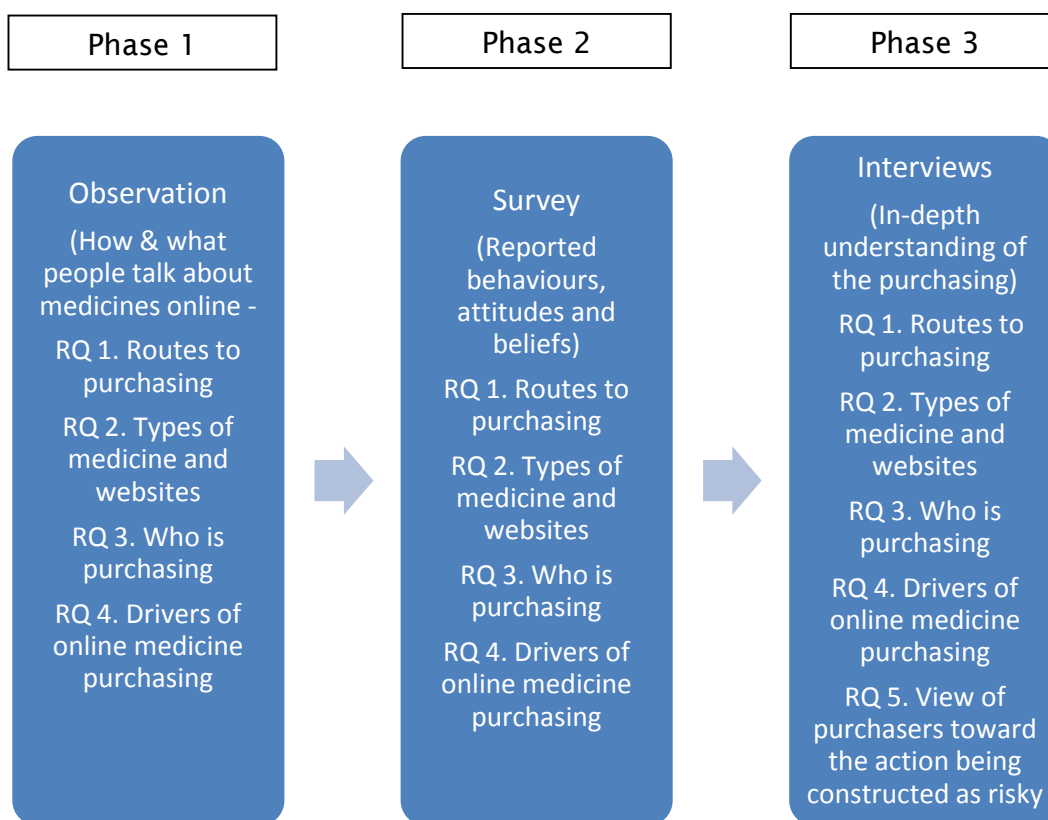
claim that my approach was netnographic. Rather, my study can be seen as a novel online methodology involving three sequential phases, and a mixed method design.

### **4.1. Research Design**

The study employed a mixed methods sequential approach, consisting of observational, survey and interview methods. The first phase involved the exploration of online forums in order to scope how people talk about medicines and online medicine purchasing. Some qualitative details relating to research questions 1-4 (*what are the routes for online medicine purchasing; what types of medicines are available for sale online and what types of websites sell these medicines; who is purchasing medicine online; what drives online medicine purchasing*) was obtained, but needed further evidencing. This information was then used to inform the design of an online survey, which looked at the behaviours involved in obtaining medicines and the attitudes and beliefs towards purchasing medicine online. The survey helped to further answer research questions 1-4 and provides a quantitative perspective to the issue. The final phase involved semi-structured interviews to explain more about the way people purchase medicine online. These enabled a qualitative, in depth understanding of online medicine purchasing, and enriched the answers to the research questions provided by the forum and survey data. The interviews also addressed research question 5 *How do people engaged in online medicine purchasing view their conduct (in light of it being constructed as risky and problematic)?* and provided the data to develop the concept of respectable deviance.

Figure 2 shows the sequential process of the methods employed in the study.

Figure 2 Sequence of mixed methods



I will now discuss each of these methods in turn.

## 4.2. Phase 1: Exploration of Online Forums

The first part of this doctoral research involved the collection of text data from publicly available web forums to inform the design of the questionnaire. These web forums are online discussion groups where people converse about topics of mutual interest. Most do not require password access or user registration, and posts are accessible in the same way as letters to a newspaper, or a conversation on a bus. It is not possible to see who is reading the conversations, but users who wish to comment identify themselves, often

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using a pseudonym. Text from forums can be gathered by a computer programme or by manual copy-and-paste functions.

After undertaking initial scoping searches of web forums, it was felt that data may differ depending on whether forums are public or private. Public forum data can be accessed with little difficulty or interaction with the group (Mann and Sutton, 1998), whereas private forums require registration and passwords to access content (Jenkins, 2001; Landreth, 1985). A number of studies have utilised data from open forums and shown that deviancy can be explored through the observation of online communities, including research on digital pirates (Cooper and Harrison, 2001), hackers (Mann and Sutton, 1998), identity thieves (Holt and Lampke, 2010), paedophilia (Durkin and Bryant, 1999) and prostitution (Blevins and Holt, 2009). A study by Schneider (2003) examined an online drugs newsgroup and revealed that its activities provided a fertile environment for users to learn how to manufacture and distribute synthetic drugs and their precursors.

The findings of Schneider's study were consistent with Mann and Sutton's previous study on deviant newsgroups (Mann and Sutton, 1998). They highlighted how users were aware of monitoring by authorities, evidenced via open acknowledgements in their posts. In order to avoid detection, messages containing criminal content, or in which crimes were being planned, were hidden from public view; personal email, encryption and private Internet Relay Chat (IRC) were used instead.

I used public forums to observe discussions about medicines and purchasing medicines online, as I wanted to observe 'naturalistic' conversations (Paccagnella, 1997), free from any potential research bias. I was also mindful of acting ethically, and thought that joining private forums would create problems with the members. This 'resolution' consequently resulted in unforeseen challenges, to which I will return in at the end of this chapter.

### **4.2.1. Forum Sampling**

Prior to initiating contact as a participant or commencing formal data collection, the researcher should become familiar with the distinctive characteristics of the online communities (Kozinets, 2002). Scoping searches online and the literature provided some information about the communities of

people who were engaged in buying medicines on the web, in particular the groups of medicines, which might be of interest.

Time was spent thinking through the research questions and possible communities that could provide an appropriate sample. Although the research was initially concerned with the purchasing of prescription/unlicensed medicine, searches were not confined to the purchase of these medicines. It was felt that it was important to understand the wider communities engaging in discussion about health and lifestyle issues relevant to buying medicine online. Additional intelligence<sup>46</sup> was sought from the Medicines and Healthcare products Regulatory Agency (MHRA), about the most popular types of medicine found online in the recent operation Pangea V.<sup>47</sup> This provided a set of health conditions, which were used as search terms on the Google search engine along with the Boolean terms of UK + health/wellbeing + forum, UK + medicine + forum or specific medicines/illnesses/symptoms + forum. This search was undertaken in October 2012, and the results are shown in Appendix 5. The initial searches returned enormous results so the first 10 pages of each were manually explored to identify forums, some of which were immediately eliminated due to their unsuitability – for example, if posts were not publicly visible, or forums did not have a UK domain.

Duplicates were discarded (n=55) and the remaining potential forums were ‘cased’ (Schatzman and Strauss, 1973) in order to assess their value and suitability for this project. By becoming familiar with the different forums, it was possible to determine whether or not pertinent conversations were being conducted, and also to gauge the amount of traffic (the number of posts and threads that appeared on there). The ‘casing’ also revealed the need to ensure that the forums chosen represented different medicines and health conditions, and potentially different demographic groups – for example by including forums dedicated to female health issues. Five key forums were purposively selected; as these represented the main types of pharmaceuticals found on the Web and encompassed a range of demographic groups. The sample was not completely representative of all online medicine purchasing as it would not be

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<sup>46</sup> A number of meetings took place between members of the enforcement team at the MHRA and myself, during the course of this research, whereby information and ideas were exchanged – specifically with regards to the findings of the forum study and the design of the online survey.

<sup>47</sup> <http://www.mhra.gov.uk/NewsCentre/Pressreleases/CON189211>

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feasible to account for every single type of medicine online that could be purchased, or to secure representation from every age group. However, there was a good spread of variety across the forums, which corresponded with the literature about the most popular types of medicine bought on the Web.

It was important to consider how to restrict the sample to UK web users for ethical and practical reasons. In order to overcome this, confirmation of location was sought from the location of the website and the users of the forums. The forums chosen were open, in that non-members were able to access and read the posts created there. The forum rules advised members about conduct and specifically warned them against the writing of offensive messages or spamming. Users of the forums were also clearly forewarned about the possibility of multiple audiences outside the forum community viewing their messages.

To provide a manageable number of cases that reflected a range of demographic groups and possible medicines/health issues, five forums were selected.

In order to comply with ethical guidelines the names of the forums have been removed; however, a short description based on my initial interpretation of them, and justification for their inclusion is provided below:

1. Forum 1: Men's health issues (discussions re: purchasing medicines for erectile dysfunction, hair loss, slimming, pain relief, cancer, bodybuilding).
2. Forum 2: Students/young professionals/"lifestyle issues" (discussions re: purchasing medicines for anxiety/depression, stress/mood enhancing, improving mental alertness (e.g. ADHD treatments being used to enhance alertness for performance in exams), STIs, abortion, morning-after-pill, contraception, erectile dysfunction/enhanced sexual performance).
3. Forum 3: General health discussion forums (discussions about purchasing medicines for other illnesses such as asthma, narcolepsy, cholesterol reduction, contact lenses, skin conditions, antibiotics, anti-histamines, anti-malarial, arthritis, sedatives, stomach ulcers and eye medicines).

4. Forum 4: Women's health, older women with families (discussions re: purchasing medicines for slimming, tanning, depression/anxiety, fertility, pain relief, cancer).
5. Forum 5: Women's health, younger, single women, links to fashion (discussions re: purchasing medicines for slimming, tanning, depression/anxiety, fertility, pain relief, cancer).

#### 4.2.2. Forum Data Collection

Manual and computerised methods were used to collect the data. Some academics claim that netnography is a content analytic technique (Langer and Beckman, 2005), rather than ethnography in the traditional sense. Indeed, the data collection techniques resemble documentary analysis, where data are collected from publicly available sources such as television, radio and public records.

Data mining is the automatic or semi-automatic collection and analysis of data (Fayyad et al., 1996). Generally, this involves processing human language texts via the use of natural language processing (NLP). NLP combines computer science, artificial intelligence and linguistics. Approaches to collecting data use software programmes that simulate the manual searching described above. Typically, they use Hypertext Transfer Protocol (HTTP)<sup>48</sup>, or a web browser such as Internet Explorer<sup>49</sup> or Google Chrome.<sup>50</sup> 'Web indexing' indexes information on the Web using software applications that run automated tasks or web crawlers that systematically browse the Web. Web scraping transforms unstructured data on the Web, typically in HyperText Markup Language (HTML - the main markup language for creating webpages and other information that can be displayed in a web browser) format, into structured data that can be stored and analysed.

Web scraping appeared to be a suitable approach for this study. Page searches were conducted using the terms (*internet or web or online*) (*medicine or drugs*)

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<sup>48</sup> <http://www.w3.org/Protocols/rfc2616/rfc2616.html>

<sup>49</sup> <http://windows.microsoft.com/en-us/internet-explorer/download-ie>

<sup>50</sup> <https://www.google.com/intl/en/chrome/browser/>

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(*purchasing or buying*). The brackets were included to ensure that at least one word within each bracket would be returned by each of the results.

The Uniform Resource Locator (URL) pages located were copied into a programme in Java,<sup>51</sup> using a library called JSoup,<sup>52</sup> and the HTML of the pages downloaded. The results of the HTML were looked at manually, via a browser (Google Chrome), to work out which HTML tags contained the links to posts on the results page. Further programming was used to extract posts, download pages, and create a file of the conversation thread. The HTML threads were examined and coded using the time and date posted and the author, and checked to ensure that at least one of the three keywords from within the brackets were included in the individual posts. The data was then saved into a CSV file<sup>53</sup> ready to be accessed in Excel.

The data was also accessed manually. To explore the chosen forums, specific keywords pertaining to the research questions were typed into the “*search topics within the forums*” search engine on the home page of the forum. Threads were read to determine their relevance to online medicine and online medicine purchasing as outlined below, and posts were manually selected by cutting and pasting.

### **4.2.3. Preparation of the Forum Data**

Relevant posts were extracted and pasted into a table in accordance with Miles and Huberman’s (1994) ‘meta matrices’ approach. Identifying information such as the time and date of the post and author ‘name’ was recorded to assist analysis (to plot the chronology of posts), but is not referred to here, in order to comply with ethical restrictions.

All posts were read to remove duplicates, advertisements or items not directly relevant to the research questions, such as discussions that used keywords in different contexts, like ‘purchasing’ relating to offline purchases in high street stores, or ‘medicine’ talked about in terms of the subject of study.

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<sup>51</sup> <http://www.java.com/en/>

<sup>52</sup> <http://jsoup.org/>

<sup>53</sup> <http://docs.python.org/2/library/csv.html>



Table 3 summarises the selection of forum posts. These refer to original posts and replies.

Table 3 Selection of forum posts

	Forum 1	Forum 2	Forum 3	Forum 4	Forum 5
<b>Posts identified as containing relevant keywords</b>	224	67	274	693	94
<b>Posts excluded after reading</b>	200	50	241	598	50
<b>Final selection</b>	24	17	33	95	44
<b>Total</b>	<b>213 Posts</b>				

#### 4.2.4. Analysis of the Forum Data

Thematic analysis was used to identify and report patterns within the data. Braun and Clarke (2006:10) suggest that a theme captures something significant about the data in relation to the research question(s). Thematic analysis enables the concise organisation of findings and is flexible enough to be applied to most situations (Braun and Clarke, 2006). It is a relatively accessible method for researchers with limited experience of qualitative research, and one that can summarise a large body of data. Themes or patterns within data can be primarily recognised in one of two ways: via an inductive or 'bottom up' way (Frith and Gleeson, 2004), or by a theoretical or deductive or 'top down' approach (Boyatzis, 1998; Hayes, 1997).

Criteria for conducting high-quality qualitative research have been previously outlined (Elliott, Fischer and Rennie, 1999; Parker, 2004; Seale, 1999;

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Silverman, 2000; Yardley, 2000). Braun and Clarke (2006) helpfully provide a concise checklist of criteria for thematic analysis, which addresses transcription, coding, analysis, timing and reporting. They suggest that data should be transcribed to a suitable level of detail and that each data item should receive equal attention in the coding process. This ensures that themes are not generated from a few examples but from a comprehensive analysis of all data.

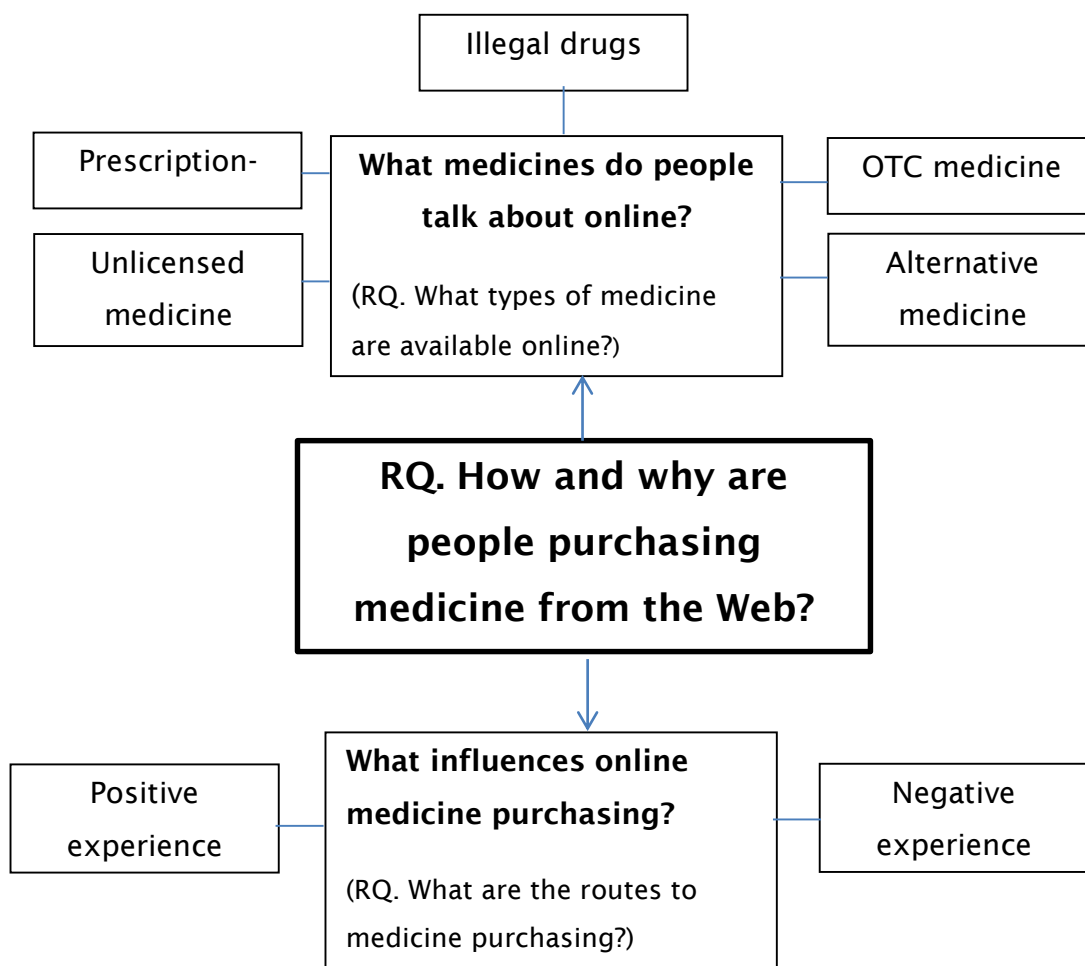
Thematic analysis followed the inductive approach outlined by Braun and Clark (2006). Guided by an interpretivist paradigm, I used a constructionist method, examining meanings and experiences as the effects of societal discourses (Braun & Clarke, 2006). Phase One involved familiarising myself with the data. Here, I looked for potentially interesting issues and patterns of meaning in the data. Phase Two involved generating initial codes, in which interesting features of the data were labelled in a systematic manner across the entire data set. Phase Three gathered all the data appropriate to each potential theme, while Phase Four involved the reviewing of themes, in order to check that themes worked in relation to the coded extracts and across the data set, and to generate a thematic map of the analysis. Phase Five involved the further defining and naming of themes to refine each theme and elaborate the overall narrative. Phase Six was focused on reporting the analysis.

Tables and mind maps were used to help develop understanding and to explore the relationships between the codes and emerging themes (Appendices). Table 4 shows the final coding frame, and Figure 3 shows one of the mind maps developed for the two themes and seven subthemes.

Table 4 Coding frame

Two Themes and Subthemes	Examples
1. What medicines do people talk about online? 1.1. Prescription-only 1.2. Unlicensed medicine 1.3. OTC medicine 1.4. Alternative medicine 1.5. Illegal drugs	Slimming medicines, erectile dysfunction, antidepressants, antibiotics, painkillers, (bodybuilding) supplements, herbal/homeopathic remedies, menopause treatments, eczema, autism, sleep remedies, legal highs
2. What influences online medicine purchasing? 2.1. Positive experience 2.2. Negative experience	Successful purchase – availability, convenient, cheap, speed, efficacy, no ill-effects, authenticity  Unsuccessful purchase – not available, not convenient, expensive, slow delivery, ill-effects, risk of counterfeit medicines, fraud

Figure 3 Mind map showing the two themes and seven subthemes



### **4.3. Phase 2: Online Survey**

The online survey was conducted in order to look at the attitudes and beliefs surrounding the purchase of medicines on the Web. The purpose of the survey was to describe the types of medicine, the types of websites that people are purchasing from and the reasons people give for purchasing them online. The survey also obtained demographical information about who is purchasing medicine online. The survey was also used as a sampling tool to recruit people to interview for Phase Three of the study.

Building on the findings of the forum study, the survey was designed with advice from the MHRA. The questions were developed in accordance with advice obtained from a CASS questionnaire design course<sup>54</sup> and Dillman's (2007) instructions on Internet surveys.

A survey development tool - isurvey<sup>55</sup> - was used to create and host the questionnaire. The survey was piloted on fellow students, friends and family members. The rule of thumb for Web surveys is that they should take 5-15 minutes to complete (Dillman, 2007), and the pilot test showed that the average completion time was 12-13 minutes.

The pilot was advertised via posts on two Facebook groups - closed/private groups for students, researchers and academics of the Web Science community, of which the researcher was a member. It was also sent to family members and friends. Forty respondents completed the pilot survey. In addition, the pilot was scrutinised by the MHRA and by three academic experts in research design. The feedback was incorporated into the design of the final survey.

The resulting survey was open to all Web users, both purchasers and non-purchasers of medicine from the Web, from anywhere in the world. The link to the survey was included in posts on Web forums (with the approval of

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<sup>54</sup><http://www.sssri.soton.ac.uk/cass/index.php>: this course showed how to write effective survey questions and combine them into a meaningful questionnaire. It focused on the design of questionnaires used in quantitative survey research, combining suggestions from the research literature on questionnaire design with a very practical approach. It covered the general principles of questionnaire design, special issues faced in writing factual, non-factual and sensitive questions for both interview and self-completion modes and an introduction to the various methods of testing questionnaires.

<sup>55</sup> <https://www.isurvey.soton.ac.uk/>

moderators); these were distinct from the forums observed in phase one of the study. It was also advertised via social media.

#### **4.3.1. Online Survey Sampling**

It is impossible to know the population size of online consumers of medicine, so the survey could not be representative. Instead, the aim was to describe the characteristics of people who buy medicine online; as such, there was no need to attempt to create a probability sample. As social researchers, we believe that patterns and regularities occur in society and these are not simply random (Rose and Sullivan, 1996). We are faced with the task of explaining why these patterns exist. Though the survey needed to be large enough to provide information about patterns of behaviour, it was used as a sampling strategy to recruit interview participants.

Sampling in qualitative research depends on the nature of the research question. Convenience sampling was used to develop the samples of the studies, as there was much that depended on whatever sources were available online at the time. A convenience sample is one that is accessible to the researcher (Bryman, 2004). The problem with this sampling strategy is that the findings are impossible to generalise, as the representative population is unknown. Convenience samples have been successfully used in social research, for example in the study of university students by Lucas (1997), and the study of the role of shopping by Miller et al. (1998). Non-coverage, though, may be less of an issue, as this research is primarily concerned with those who are using the Web and so by looking at Web data the research ensures that it is targeting the right community.

Some snowball sampling techniques were also used as I recruited participants from networks of my associates, both on and offline. Snowball sampling uses existing study subjects to recruit other subjects from among their acquaintances (Goodman, 1961).

#### **4.3.2. Online Survey Data Collection**

The survey was launched online on 1<sup>st</sup> July 2013 and ran for six months until 31<sup>st</sup> December 2013. It was advertised via social media such as Facebook and Twitter, using my personal and professional networks. I created new accounts

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on both Facebook and Twitter to promote the survey, but also linked these to my existing personal profiles. I sought advice from experts on Web marketing and social media in order to determine the best strategy for recruitment. The survey was also promoted via LinkedIn, and a group was specifically created there to discuss medicines on the Web.

I also sought permission from forum moderators to post messages containing the link to the survey on forums, which discussed related issues, for example the Bluelight forum, which is a dedicated area for conversations about drugs, drug use and drug research, and patient.co.uk, which covers health information. Incidentally, they also allowed me to advertise using their Facebook page. Other forums I utilised included the PhD and academic forums, as they form part of the research community and it was interesting to discover similar research.

I approached high-profile companies to ask them to advertise the survey. I sent tweets to Drugscope and other related drugs charities and health services with thousands of followers, asking them to retweet my messages. Sometimes my requests were viewed as spamming and caused my account to be closed temporarily. Nevertheless, some major associations did retweet the messages, as did some of their followers in turn.

The survey drew in respondents slowly. By this time I was participating in the University of Southampton's very first Massive Open Online Course (MOOC) in Web Science. This was a free course that is conducted via the Web. As part of this MOOC, I filmed a video about my research, and with permission from the MOOC organisers, a link to the survey was included on the page where my video was based. People were under no obligation to complete the survey and their participation was entirely voluntary. Responses were enthusiastic during this latter period, and the final number of complete surveys returned was 240.

Comparisons may be drawn with the recruitment process for the Great British Class Survey (GBCS) conducted by Savage et al. (2013), though the sample for my research is much smaller. The GBCS was publicised across BBC television and radio, as well as in newspaper coverage, and the resulting response rate was huge (161,400 complete responses). As with my survey, well-educated and professional groups were massively over-represented. To overcome this limitation, a separate nationally representative face-to-face survey using

identical questions was also conducted as part of the Great British Class Survey.

The survey data was not weighted as the sample was recognised as unrepresentative, and tackling the bias of the overrepresentation of the MOOC respondents would not have fixed this.

#### **4.3.3. Analysis of the Survey Data**

The approach used in this study followed an exploration of the data, where relationships were teased out and tested for association or causation.

The first step in analysing statistical data is to investigate the distribution of the variables of interest. Deriving indicators of the distribution such as the frequency, mean and percentiles in the data is helpful, for example, when comparing the opinions of people who buy medicine online with those who do not.

The survey contained 42 questions in total across five domains, filtered depending on answers to earlier questions. The five domains were:

1. Demographics
2. Behaviour and attitudes regarding buying medicine from the Web.  
Respondents indicated whether or not they had bought medicine online or not, and attitudes towards this activity
3. Knowledge about medicines and medicine use
4. Sources of (health) information
5. Perceptions about safety and risks relating to the purchase of online medicines

The data was input to SPSS ready for analysis. Numeric codes were assigned to the closed and predefined answers. Open questions, where the range of possible answers was not decided on in advance, or where text comments were collected, were not coded but were thematically analysed.

The SPSS database consisted of 53 variables and 229 categories. Questions included yes/no responses, but beliefs and attitudes were assessed using five-

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point Likert scales (ranging from strongly agree (1) to strongly disagree (5), and from almost always (1) to never (5). Multiple-choice questions explored patterns of activity and sources of information/medicines. Descriptive statistics were used to analyse demographic data and respondents' behaviour and attitudes, knowledge and sources of information. Missing responses were excluded but are distinguished from questions that included the response 'prefer not to say'.

### **4.4. Phase 3: Semi-Structured Interviews**

The third phase of the study involved explanatory semi-structured interviews. The purpose of these was to explore qualitatively the quantitative results from the survey and to obtain a richer understanding of how and why people are purchasing medicine online in order to address research questions 4 and 5 (*what drives online medicine purchasing; how do people engaged in the behaviour view their conduct*). The interviews were informed by the preceding phases, and covered views of past and present medicine purchasing from the Web, behaviours towards the obtaining of drugs and medicines, and how decisions are informed and made.

A list of questions, which covered some fairly specific topics, was produced from the analysis of the survey data and used as a guide throughout the interviews. In semi-structured interviewing, the interview process is flexible and the emphasis is on the way the participant frames and understands issues and experiences (Bryman, 2007). Following Leidner (1993:238), a topic guide was used to provide a degree of structure but also to allow room to pursue topics of particular interest to the participant.

The answers provided in the survey assisted the creation of this interview guide, and interviews were tailored for different respondents. The questions differed depending on whether the participant had indicated that they had or had not bought medicine from the Web.

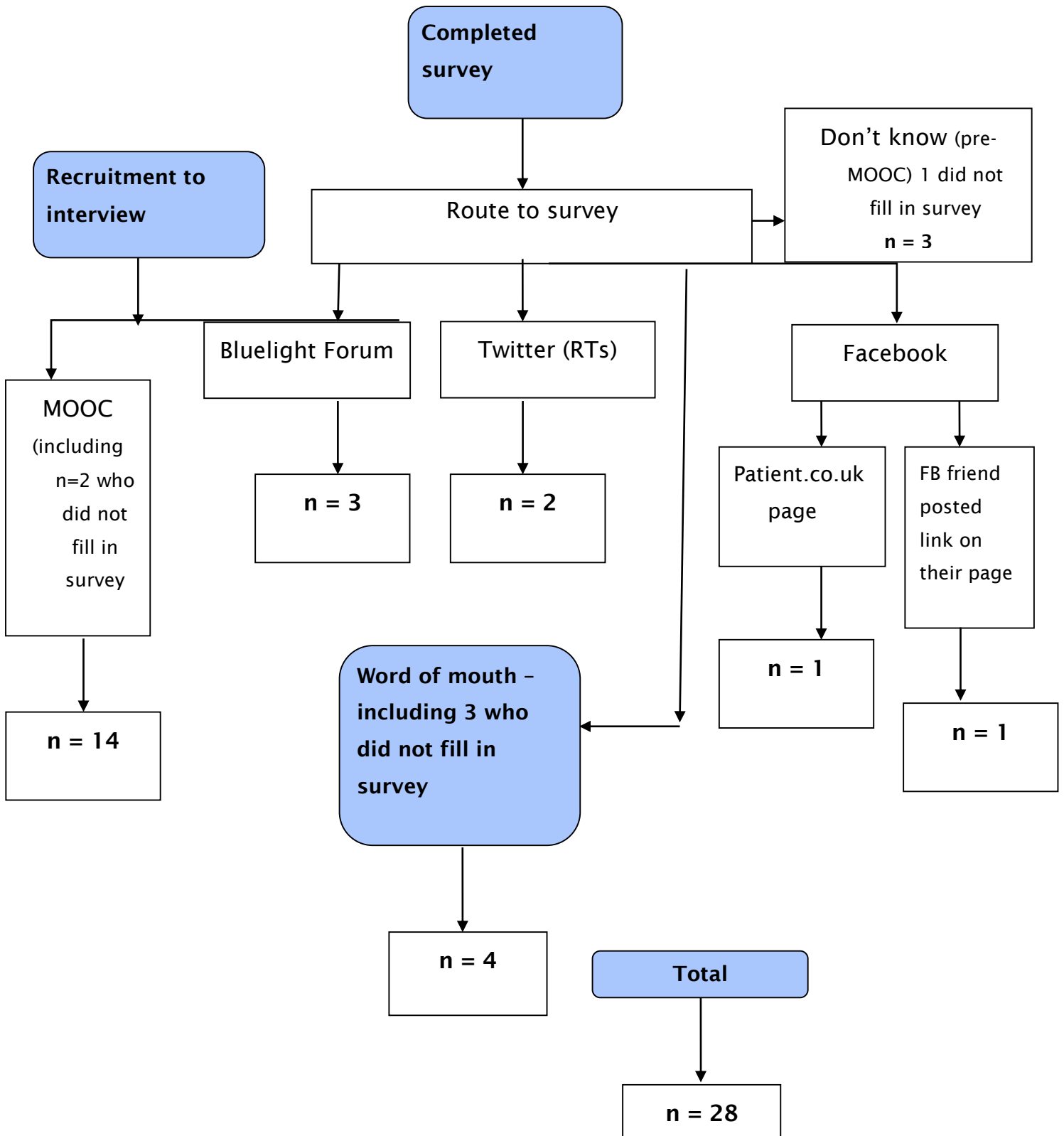


#### **4.4.1. Interview Sampling**

In accordance with Fitzpatrick and Boulton (1994), it was necessary to ensure that sampling contained the full range of possible perspectives so that the concepts and categories developed provided a comprehensive conceptualisation of the subject. The survey included the option for participants to agree to being contacted in order to take part in follow-up interviews by providing their email address. They were sent consent forms and study information sheets, which were signed and returned prior to the interview. Convenience sampling was used, as much depended on which of the respondents to the questionnaire study provided their details for a follow-up interview and then consented to being interviewed. Snowball sampling was also used, as I advertised on social media and via contacts.

Most of the interview participants were recruited through the online survey; however, six participants were recruited via word of mouth and the MOOC, and contacted the researcher directly to be interviewed. A breakdown of the route to interview and route to the survey (if applicable) is provided in Figure 4  
Consort flow diagram: route to survey

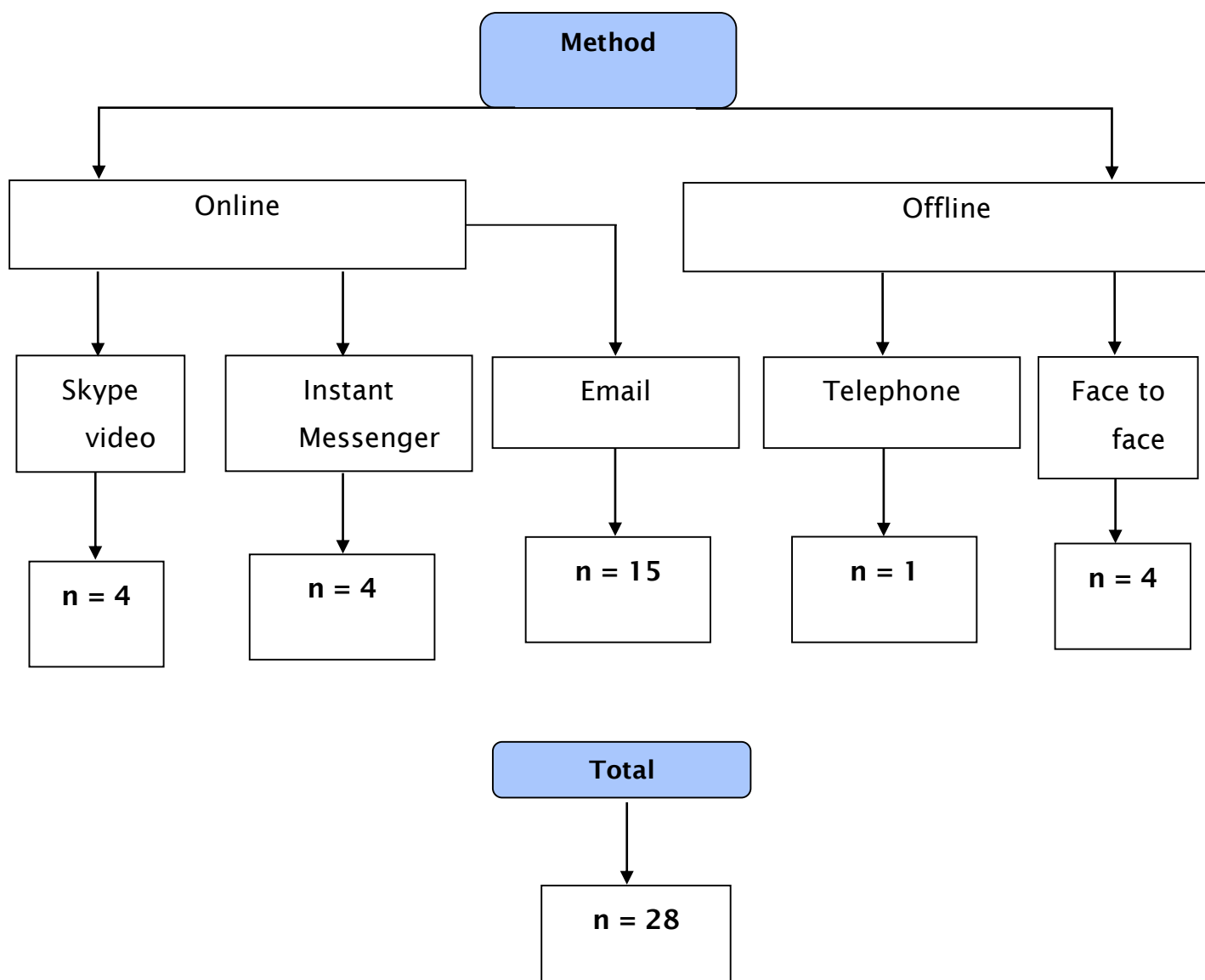
Figure 4 Consort flow diagram: route to survey



#### 4.4.2. Interview Methods

A range of different interviewing methods was used; these are displayed in Figure 5 Consort flow diagram: method of interview.

Figure 5 Consort flow diagram: method of interview



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This study mediated between the virtual field and the real field by combining online and offline interactions and communication in the different methods of interviewing employed. These included more traditional means such as face-to-face and telephone interviews, but also innovative techniques benefitting from contemporary technology like Instant Messenger (IM), Skype video messaging and email. Some online techniques were not dissimilar to their offline counterparts. Face-to-face interviewing is comparable with Skype video interviews, as both the researcher and the participant can observe body language and respond accordingly, while IM, telephone interviews and email interviews do not benefit from a physical presence.

According to James and Busher (2009), the inclusion of both verbal and non-verbal cues such as facial expressions, gestures, postures and emotional mannerisms in face-to-face interviews enhance the social interaction. The immediacy of social presence taking place in 'real-time' is a pivotal part of the research relationship (James and Busher, 2009). This is also true for Skype video interviews, where the researcher and the interviewee benefit from being able to read the other's body language. In contrast, telephone interviews have been criticised for their absence of visual cues (Garbett and McCormack, 2001).

Henson et al. (1978) suggested that although the face-to-face method might facilitate openness, participants might be subtly induced to untrue admissions, whilst telephone participants have been described as relaxed and willing to talk freely and disclose intimate information (Novick, 2008). I found that different methods offered different benefits. I expected the topic might prevent some interviewees from revealing some details from their private lives or health experiences. However, this was not the case, as interviewees talked about how they had not told their friends and family about purchasing medicine online for fear of negative reaction. The stranger "*often receives the most surprising openness – confidences which sometimes have the character of a confessional and which would be carefully withheld from a more closely related person*" (Simmel, 1950:404). I generally found that face-to-face methods procured a larger amount of data than email interviews, which tended to encourage short, focused answers; however, I was able to return to the email conversations and resume questions if I felt that the data needed to be elaborated. This was not possible with the face-to-face interviews, which were

usually under time constraints. The majority of the email interviews were iterative processes, not confined to single conversations but continuing on over several days.

By using different interviewing methods, valuable data were collected from people who may otherwise have not been able to participate, and the techniques were tailored to their needs. IM and email interviewing avoided interview fatigue, as well as concerns about the safety of the researcher, and increased the geographical reach of the research.

The chapter now turns to the specific issues I faced during the interviews.

#### **4.4.3. Temporal Issues in Asynchronous Interviewing**

Asynchronous interviews such as IM or email interviews are not conducted in real-time, so participants are able to reread what they have previously written, reflect on and consider their responses and amend their text. In synchronous interviews, responses are spontaneous. There has been considerable debate about the reflexive nature of the online medium (Markham, 2004).

Asynchronous email discussions can allow for an extended and deliberate sequence of conversations, and enable researchers and participants to digest messages before replying (Kanayama, 2003). Kivits (2005) states that participants have the time and space to refine their own thinking without intrusion by the visual presence of the researcher, which allows the development of a more thoughtful and personal form of communication. Johnson (2011) claims that the semi-anonymity of online communications encourages people to self-disclose more than it hinders them from doing so. Bowker and Tuffin (2004) also note that the ability of participants to reflect on their thoughts and reactions can be enhanced as a result of the intimacy furthered by the informality of typing.

I encouraged participants to review their previous correspondence and to revisit earlier topics in order to help the development of their thinking about other issues. I returned participants' messages to them as part of the normal email exchange, so I kept to the thread of email messages rather than starting each email anew. I did not erase any messages from the exchange, in order to ensure that the participants and I were able to interrogate earlier texts as our dialogues developed. This proved useful during one occasion where I was

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accused of repeating a question, yet inspection of the past exchange proved that this was not the case.

My attitude towards having to wait for responses from my participants changed over the course of the interviews, from trepidation and concern that the participant had lost interest in the study to anticipation of the possibility of obtaining exciting information. As Russell and Bullock (1999:134) put it succinctly, *“one of the beauties of e-mail is that you never know when you will get a response...”*

### **4.4.4. Interview Data Collection**

28 interviews were carried out over a period of four months, from November 2013 to the end of February 2014. Experiences of healthcare and purchasing medicine online formed the main focus of discussion. The average length of time for these interviews varied, as different methods were used. The face-to-face and Skype interviews typically lasted for an hour, while the IM interviews lasted between one and a half hours and three hours, and the email interviews took place over several days. Towards the end of my interviews it was clear that I was not generating any new information, and so it was felt that it would not be worth pursuing any more than 28.

Interviews were recorded using a tape recorder for face-to-face, telephone and Skype video interviews, and the text of the dialogue was automatically generated in IM and email interviews.

Table 5 shows the interviewees by age, gender and their purchasing status.

Table 5 Breakdown of interview participants' ages

	Men			Women		All
Age range	Purchaser	Non - purchaser	Not known	Purchaser	Non - purchaser	
18-24	1			1		2
25-34	1	2		3	2	8
35-44	1	1		3	2	7
45-54	1			3	1	5
55-64	1		1	1	2	5
65 and above	1					1
<b>Sub-total</b>	6	3	1	11	7	28
<b>Total</b>	10			18		28

The interviewees were predominantly White British and primarily based in the UK. The over-representation in the survey of the MOOC participants, who were more highly educated, meant that most of the interviewees had also attained a high standard of education. In order to make the survey more representative I did try to seek out participants from different social groups (i.e. across the range of employment options) and ethnic groups (although this information was collected I did not include it within my analyses because of limited data), however, I was limited with my convenience sampling and where I was able to advertise and distribute the survey online. Upon reflection, the online spaces that I used – social media and forums, ended up attracting particular homogenous groups.

#### 4.4.5. Analysis of the Interviews

The analysis drew on Mason's (1996) cross-sectional and categorical indexing. This approach was used to obtain an overview of the data and generate themes. Mason (1996:54) outlines three approaches: "*literal, interpretive, and reflexive*". Literal indexing focuses on the exact use of particular language or grammatical structure. Interpretive involves making sense of research

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participants' accounts. Finally, the reflexive approach attempts to focus attention on the researcher's contribution to the data creation and analysis process.

As per Mason's (1996) suggestion, in practice I used a combination of these approaches. To begin with, I organised the data by coding text and breaking it down into more manageable chunks. I created initial indexes (see Appendices) consisting of in vivo codes identified in the data, and my interpretive codes. During this process I regrouped and revised codes, and organised them into lists to see the connections between them.

I sorted and grouped categories together and wrote an overarching description for each (akin to a memo in grounded theory). The data was then coded and input to the computer-assisted qualitative data analysis software package NVivo, which helped to construct the themes.

## **4.5. Ethical Approval**

This study received initial ethical approval from the Faculty of Health Sciences Ethics Committee at the University of Southampton (see Appendix 3). Further ethical approval was sought during data collection, when the study design had to be adapted. The amended submission was approved on 10/10/13 (Submission Number 6157) (Appendix 4). The ethics approval allows use of the data obtained from automatic web scraping, providing that the online usernames are removed and that no reference is made to the names of the specific websites used. Approval was also subject to the proviso that there is no breach of the terms and conditions of the websites used.

Ethics played a substantial role in my study due to unexpected and unique issues that arose during the collection of my data. Examination of the literature and guidance in this area revealed inconsistencies and gaps; therefore ethics is a vital part of this thesis. In what follows I will briefly address ethics and their application in online research, before going on to describe the specific ethical challenges I faced.



#### 4.5.1. The Ethics of Online Research

The Web has opened up a rich source of data, both quantitative (e.g. user statistics) and qualitative (e.g. user-generated textual content such as blogs). These online data can provide access to first-hand accounts of individuals' experiences with purchasing medicines online. However, the use of digital data presents a number of new ethical challenges. Though online research may be held accountable to established ethical considerations and guidance, the claim of this thesis is that new guidelines are needed in this area.

#### 4.5.2. Research Ethics – The National and International Landscape

Ethics can be understood simply, as morals or rules of conduct. Some core tenets shared by various legislation and policies relating to ethics and wider human rights include the rights to dignity, autonomy, protection, safety, maximisation of benefits and minimisation of harms. These have origins in ethical and philosophical debates dating back to Aristotle and Socrates, identifying moral behaviours and right and wrong conduct. Historical atrocities such as the Holocaust, along with notorious academic studies, which though undoubtedly not as unethical, used controversial ethical procedures (Milgram, 1963, 1974; Zimbardo, 1971), have also influenced ethical debate and law, and inform contemporary research practice.

Principles of research ethics and ethical treatment of persons are codified in a number of national and international policies and documents, such as the UN Declaration of Human Rights, the Nuremberg Code, the Declaration of Helsinki and the Belmont Report. On an international level, privacy rights are primarily dealt with by Article 8 of the European Convention on Human Rights (ECHR Human Rights Act, 1998<sup>56</sup>), which protects the right to respect for private and family life and correspondence. In the UK these ethical considerations are linked, but not restricted to, legislation enshrined in the Data Protection Act 1998 (DPA<sup>57</sup>), which governs the protection of personal information. Although the Act does not reference privacy specifically, it is designed to protect people's fundamental rights and freedoms and in particular the right to privacy

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<sup>56</sup> <http://www.legislation.gov.uk/ukpga/1998/42/contents>

<sup>57</sup> <http://www.legislation.gov.uk/ukpga/1998/29/contents>

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in relation to the processing of personal data. This means that data must be kept securely and does not lead to a breach of confidentiality or anonymity. Compliance with the Act is regulated and enforced by an independent authority, the Information Commissioner's Office.<sup>58</sup> Individuals who feel that use of their data has breached the principles of the DPA can report their misgivings to this office. Research may also be subject to the ECHR and the DPA; this is distinct from guidance issued by learned societies (e.g. the British Sociological Association). Legislation concerns rights, which may be enforced and involve litigation, while guidance from learned societies address codes of conduct, which if breached might be dealt with according to the specific practices of the society rather than involving the rule of law.

Despite these various codes and guides, practice varies. For example, in his book, *Drugs 2.0: The Web Revolution That's Changing How the World Gets High*, Power (2013) openly admits to using covert and deceptive methods on web forums, where he posed as an international buyer of both legal and illegal substances. Such practices, while possibly acceptable in journalistic research, are not allowed in academic research. To some extent, journalists have the freedom to oversee their own self-monitoring and self-correction. Market research also appears to have more lenient, self-regulating guidelines, relying on forms of best practice, to enhance the development and use of marketing, social and opinion research. The capacity of the market researcher to do their job, albeit in a professional manner, is paramount. In contrast to news media and market research, academic institutions have to respond to national and international legislation, and take account of guidance and best practice. Institutions employ formal ethical procedures for their research projects in order to avoid litigation, and have a significant focus on obtaining informed consent from research subjects and anonymising data.

### **4.5.3. Institutional Ethics**

In response to law and guidance, academic institutions have developed formal bureaucratic procedures to manage research ethics. Researchers engage with systems of review to ensure that research is methodologically and ethically sound (Wiles, Clark and Prosser, 2011). However, it has been suggested that

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<sup>58</sup> Full details can be found at <http://www.ico.gov.uk>

the increasing formalisation of ethics review has caused difficulty for researchers using online methods (Orton-Johnson, 2012). Sikes and Piper (2008, 2010) also criticise ethics review committees for positioning researchers as irresponsible. Consistency is also an issue, as there appears to be different procedures in different disciplines; for example, computer sciences have been slower to consider ethics and adopt formal governance than social sciences. Other disciplines, notably medicine and health sciences, have more developed systems and processes for ethics review. Indeed, healthcare is at the forefront of formalising ethics, perhaps due to the responsibility of minimising the risk of harm to patients and the public.

International ethical codes for healthcare research draw on the broad framework of ethics and human rights already discussed, and focus on informed consent, anonymity, privacy, confidentiality, harm minimisation and risks to research participants.<sup>59</sup> In the UK, research involving the National Health Service (NHS) or patients requires review by the NHS's National Research Ethics Service (NRES). The NRES ensures that health research involving members of the public is ethically reviewed and approved. This process runs in addition to the local institutional ethics review undertaken by university based ethics committees. This chapter will now turn to the ethical issues of web research in particular.

#### 4.5.4. Web Research

The Web has opened up new research possibilities. Eynon et al. (2008:1) describe it as a huge "*social science laboratory*". The Web enables the opportunity to collect and collate different types of digital qualitative and quantitative data, and in doing so creates new challenges for research ethics. Policies and frameworks governing ethics in research predate the Web, and further complications arise from the fact that the global reach of the Web means there are different legal and ethical regulations in different jurisdictions. The use of traditional ethical guidelines in the online research world is contentious (Grinyer, 2007:1). It has proved very difficult to operationalise existing guidelines for research on the Web. However, this

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<sup>59</sup> World Medical Association. WMA Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects, 2004. <http://www.wma.net/en/30publications/10policies/b3/>

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thesis suggests that special ethical considerations are necessary when conducting online research because of the specific issues concerning consent, privacy and anonymity in this domain.

The issue of consent in online research is particularly challenging, especially in relation to data from social networking sites and other user-generated content such as forums and blogs. Ethnographic methods have been used for research on such sites (Eynon et al., 2009; Snee, 2009). However, there is conflicting opinion about whether it is necessary to obtain informed consent in these research settings (Hooley et al., 2012; ESS, 2002). It has been suggested that informed consent should always be obtained for research based on private communications and which take place in private or semi-private areas, but that in open access areas, which are understood as public, informed consent is not essential (Wiles, 2012). However, the distinction between what is acknowledged as public and private is blurred and ambiguous because there are no clear boundaries, and people may not be aware of the public status of their conversations and actions online. Web research can access large amounts of user-generated content, and documents that are publically accessible. There may also be semi-private documents/texts, which require membership of online groups to view them. In addition, it is possible to collect quantitative activity data, the record of any user action logged on a computer.<sup>60</sup>

One response to this new public space has been to simply observe. ‘Lurking’ in online communities, where someone observes but does not participate or announce their presence, is a known phenomenon, and has been adopted by researchers wanting to undertake ‘naturalistic research’ (Paccagnella, 1997; Hine, 2000). Research using material published on the Web does not involve direct contact between the subject and the researcher; as such, one of the main problems faced by qualitative research, namely that of data being somehow influenced by the researcher and research process, is avoided. Data obtained from online public environments is welcomed because it allows

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<sup>60</sup> Activity data can be thought of as falling into three categories:

**Access** - logs of user access to systems indicating where users have travelled (e.g. log in/log out, passing through routers and other network devices, premises access turnstiles).

**Attention** - navigation of applications indicating where users have been and are paying attention (e.g. page impressions, menu choices, searches).

**Activity** - ‘real activity’, records of transactions, which indicate strong interest and intent (e.g. purchases, event bookings, lecture attendance, book loans, downloads, ratings).

[http://www.activitydata.org/What\\_is\\_Activity\\_Data.html](http://www.activitydata.org/What_is_Activity_Data.html)

access to diverse and/or potentially unreachable groups, which is especially useful in studies observing deviancy (Mann and Sutton, 1998; Holt, 2007).

However, lurking and collecting publicly available data without the subject's knowledge or consent is covert research. There has been much discussion about what is public and private online, and it is acknowledged that users may have contradictory views about their privacy (Wiles, 2013). Covert research is controversial; the use of deception to obtain information is viewed as potentially harmful to research participants, and so this practice is generally vetoed in research. A consequentialist ethical position follows the premise that ethical behaviour should be determined by the consequences of an act (Anscombe, 1958; Thomas, 1996). The goal of an act should be that which results in the greatest social good or the least social harm (Capurro and Pingel, 2002). To date, researchers have used these types of arguments to justify gaining access to research settings covertly on the basis that their work contributes to the public good. Some online researchers have used the same arguments to justify lurking, stating that it is the only way to obtain information on an important issue (Thomas, 1996).

In response to some of these issues, frameworks have been developed to assist with such ethical challenges. These are from the Association of Internet Researchers (AoIR), The British Educational Research Association (BERA), The Market Research Association (MRA), The Council of American Survey Research Organisations (CASRO), The British Psychological Society (BPS) and The British Society of Criminology (BSC).

#### **4.5.5. Web Research Guidance**

Each of these learned societies offers some guidance about ethics in web research. These will be briefly summarised in turn to provide an overview of the assistance available to online researchers.

The Association of Internet Researchers (AoIR) has produced some ethical guidelines for online research (Ess and AoIR, 2002; AoIR, 2012), but this is still subject to some debate and disagreement (Eynon et al., 2008:23). Lomborg (2013) discussed how the AoIR is advocating a bottom-up case-based approach to research ethics. This emphasises that ethical judgment must be based on a sensible examination of the unique object and circumstances of a study, the

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research questions, the data involved, the type of analysis to be used and the way the results will be reported – with the possible ethical dilemmas arising from that case.

The British Educational Research Association Ethical Guidelines (BERA) (2011) has a particular focus on avoiding harms when considering online research. Hammersley and Traianou (2012) discussed the minimisation of harm – specifically, whether a research strategy was likely to cause harm and if so how serious it would be, and whether there was any way in which it could be justified or excused. Harms might arise from asking for consent, or through the process of asking for consent, and can apply to both the forum members and the researcher; the act of sending participation requests may in itself be intrusive.

The Market Research Association (MRA) guide to the top 16 social media research questions stipulates that researchers should learn about and be comfortable with important explanatory variables beyond traditional respondent demographics, such as how different websites generate and facilitate different types of data (e.g. whether data is more positive versus negative, descriptive versus condensed etc.) In social media research it is commonly understood that conversations are generally public and viewable by almost anyone, and as such the individual under observation may or may not be aware of the presence of a researcher. This can lead to the likelihood of “social observational bias”. Users may participate in social media for different reasons (e.g. personal or professional) and this can affect the type, sincerity and direction of the user’s comments, which may be unrecognised by the researcher. Informed consent is encouraged when research might prejudice the legitimate rights of respondents, and researchers should exercise particular care and consideration when engaging with children and vulnerable people in web research; however, the Market Research Society/Market and Social Research (Esomar) states that if it is public data there is no need for informed consent. These guidelines structure the choices that researchers make about procedural and resulting ethical issues.

The Council of American Survey Research Organisations (CASRO) social media guidelines suggest that where participants and researchers directly interact (including private spaces), informed consent must be obtained in accordance

with applicable privacy and data protection laws. However, it is unclear whether pure observation, where data is obtained without interaction with the participant, would fall under this remit, as no direct reference to this type of research is offered.

The British Psychological Society and the British Society of Criminology have also updated their guidelines to include online research.<sup>61</sup> These take into account the problems that may arise, such as legal and cultural differences across jurisdictions, online rules of conduct and the blurring of boundaries between public and private domains. However, there is still no clear direction to follow.

The frameworks for the AoIR, BERA, MRA, CASRO, BPS and BSC provide some starting directions for online research; however, they do not address all the ethical challenges that can arise. In addition to this guidance from learned societies, some researchers have also suggested processes for undertaking online research. Nind et al. (2012) refer to the tensions inherent in the interaction between ethics and methodological innovation, and recommend exercising caution, as well as being creative, in these new Web spaces. They suggest adopting a reflexive position and demonstrating a strong commitment to acting responsibly while moving forward methodologically. Kozinets also deals with online research (Kozinets, 2002), and contends that the researcher should fully disclose their presence, affiliations and intentions to online community members during any research. He states that researchers should ensure the confidentiality and anonymity of their informants and places the onus on the researcher to seek and incorporate feedback from members of the online community being researched. The netnographic approach requires the researcher to contact community members directly and obtain their informed consent to use any specific postings for the research (Kozinets, 2002:65; Kozinets and Handelman, 1998).

However, Langer and Beckman (2005), in their study utilising online discussion boards dedicated to conversations about cosmetic surgery, claim that Kozinets's ethical stipulations of netnography, where the obtaining of informed consent is compulsory, are too restrictive. They suggest that such ethical

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<sup>61</sup> <http://www.bps.org.uk/what-we-do/ethics-standards/supplementary-guidance-use-social-media/supplementary-guidance-use-social-media> <http://www.britisoccrim.org/codeofethics.htm>

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guidelines make sense in private online communities and when participating in traditional ethnography, but are far too rigorous to be applied in the same context online, and basically endanger the unobtrusiveness of online communication studies. If there is free public access to the data, they suggest instead relying on research ethics established for content analysis, which have been developed in media and communication. Langer and Beckman's (2005) data collection was based on a pragmatic position towards covert research. They claim that their chosen procedure fully satisfies the ethical standards for content analysis of public media texts. A comparable example would be an analysis of readers' letters in newspapers. The disclosure of the researcher's presence by contacting community members to obtain permission, which is a duty suggested by Kozinets (2002:65), would diminish one of the major advantages of content analysis – namely its unobtrusiveness. In addition, they point out that it would potentially endanger the whole of the research project if participants opposed the research. Furthermore, some hesitant users might engage in what Langer and Beckman (2005) refer to as 'the spiral of silence', by not producing posts. This would immediately result in misrepresentations of consumer accounts of a given topic, where only the most confident and articulate users would be included in the analysis.

Hammersley and Treseder (2007) set a precedent for online observational research in their study of pro-anorexic websites. Research utilising data from social media such as Twitter provides further examples of this approach, where studies have been conducted with little or no ethical consideration (Signorini et al., 2011; Vieweg et al., 2010; Honey and Herring, 2009). Guidelines for Internet research allow scrutinising of the content of open-access discussion forums without the express permission of the website moderator or the contributing parties (Fox et al., 2005). Guidelines provided by the Association of Internet Researchers,<sup>62</sup> relating to the use of special interest forums for research, highlight the importance of data being easily searchable and retrievable; the discussion threads from the forums in this case were all easily identifiable from public searches. The British Society of Criminology guidelines<sup>63</sup> suggest that informed consent should usually be sought, but other

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<sup>62</sup> <http://aoir.org/reports/ethics2.pdf>

<sup>63</sup> <http://www.britisoccrim.org/codeofethics.htm>



researchers contend that much online data is situated in the public domain, and is therefore comparable to television or newspaper articles (Kitchin, 2003).

Having set the scene for key ethical issues and current guidance, I will now explain how I put this into practice in my research – this reveals some of the difficulties in meeting these ethical ideals.

#### **4.5.6. Putting Ethical Guidance into Practice in my Research**

For the first phase of the study, the observation of online forums, Kozinets' (2002) framework for online ethnographic work was initially followed. Although informed consent was not legally required to access these data, as they were in the public domain (as with much of the Web, the legal frameworks and case law have yet to be made to govern this aspect of digital technology), I still encountered ethical problems.

Based on advice from the Health Sciences ethics committee and the Research Governance office at the University of Southampton, and following Kozinets' (2002) advice, the study initially followed the overt informed consent route. I openly joined the forums identifying myself as a 'researcher', and created posts under the subject title of 'Researcher requesting information on this forum'. The posts were designed to inform the forum members that I was collecting data and to outline the research. The posts provided forum members with the option of contacting me if they did not wish their posts to be used. The post was to be reposted each week to ensure that as many forum members as possible were aware of it and would have the option to contact the researcher. This took into account the fluid membership of online groups (King, 1996), as repeatedly advertising the presence of researchers at the site (Stone, 1995) allows participants to choose whether to be involved.

In practice, my overt presence within the forums proved antagonistic. Some members posted abusive and suspicious comments in response to posts, and moderators of some of the forums removed some threads relating to the posts. Some posts were not even allowed on to the forums, with moderators stating that this would upset the members, and suggested that the research should just be conducted without notifying them. One site asked for payment

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for the posts. Some members asked why I was asking to use public information; other forum members were concerned about the legal implications of their conversations, and whether what they were saying could be passed on to the authorities.

After discussions with the supervisory team the forum data collection was temporarily suspended to seek further advice from the University ethics committee. The University legal advisor advised me that forum posts are not personal data (under the DPA), therefore I did not have legal liability/responsibility to report actions reported on virtual forums. It was pointed out that just because people are saying that they are buying and selling regulated or unregulated medicines online does not necessarily mean that they are, and that I had no means of verifying behaviour. The MHRA advised that the regulatory position was that it is not a criminal offence to discuss the purchase of prescribed or unlicensed medications online.

While I was reassured about the legal and regulatory position vis a vis my research, I was still concerned about ethics. I submitted an amendment to the ethics committee, asking to be allowed to collect and view public and largely already anonymised data for the thesis, following the style of passive analysis as outlined by Eysenbach and Till (2001). I felt that this was an important and necessary component of the research, as it would inform the questionnaire and the preliminary analysis would be useful in the thesis. I was eventually granted permission to use the anonymised forum posts. I only used those posts, in the event, from a single scraping exercise. I utilised quotations but removed any identifying attributes such as the website and forum name, the forum user's pseudonym and the time and date posted. I also removed spelling and grammatical errors, and summarised conversations in order to avoid the quotations being easily discoverable via search engines.

Planning the following phases of the study, the online survey and the semi-structured interviews, was more straightforward, and I focused on obtaining informed consent and anonymising the data. However, here too I encountered unforeseen ethical issues.

For the online survey, completion and return of the questionnaire was sufficient to indicate consent. Participants voluntarily responded to links placed on the forums, social media and the MOOC. To proceed to filling in the

survey, they were asked to read the study information sheet and tick the consent form. The survey data had unlinked anonymity, as respondents could not be traced, and the questionnaires were not targeted and did not contain any names, addresses or other identifiable characteristics. Data was coded, and only aggregated anonymised analyses have been used in this thesis.

Prior to commencing the interviews, participants were provided with the study information sheet and a consent form, which they completed and returned to me. The participants were aware that the interview was recorded and transcribed, and had the option of leaving the interview at any time along with choosing not to allow their data to be used within the research. After the interview, participants received a further reminder about the way the data was to be used and stored. Explicit consent was sought to use the data; however, any information that could identify the participant was removed. The participants of the interviews had linked anonymity, as they could be traced via their emails once they agreed to participate in the interviews; however, this information was only known to me and their identification was protected by data protection procedures. Their data was coded and pseudonyms used, and no personal information such as email addresses has been included in this thesis.

My research raised ethical issues relating to informed consent of human subjects, protection of privacy and anonymity of research subjects. This chapter will now address these issues in turn.

#### **4.5.7. Informed Consent in Online Research**

Obtaining informed consent online may involve the researcher posting to communities or individually contacting users and providing them with participant information sheets and consent forms to sign. However, there are practical difficulties involved in procuring informed consent from all members of online communities, as not everyone may see posts, and some members may have left, leaving their contributions still visible.

Langford (1996) suggests that it would be advantageous for researchers wishing to conduct analysis of posts and archives to consult the introductory notes or terms of electronic forums. Terms may openly request that research should not be carried out on the forum. Where clear directives do not exist, it

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may be possible to contact the list moderator and gain permission to conduct research. However, researchers need to bear in mind that any permission gained may not necessarily be viewed as consent by all members of the group (Reid, 1996). Whether consent needs to be obtained from individual contributors or from communities and online system administrators is fraught with uncertainty. The issue of ownership/intellectual property of the data may be addressed in the terms and conditions, but the moderators cannot speak for people they do not know personally. Even if they did, it would not be sufficient to form a legally binding contract in the real world, so they cannot really be considered gatekeepers online.

However, as my research revealed, seeking such permission can also create further ethical problems. In other studies, researchers have sought informed consent and found similar unforeseen impact on group processes. King (1996) cites one member of an email support group who, in response to continual posts to the list from people wishing to conduct research, refused to “*open up*” online to be “*dissected*” (1996:122). Hewson et al. (2003) also question whether contacting potential participants may be viewed as “spamming”, itself an invasion of privacy (Hewson et al., 2003:40).

While informed consent is desirable, it is not always essential. In “non-participant observation” it has been accepted that behaviour conducted within the public domain may be observed and researched without consent (British Psychological Society, 1993). The justification for this exception is to ensure that natural behaviour is observed in its context, without contamination by the researcher’s aims and objectives. Similar arguments have been made for covert observational research. The famous study conducted by Laud Humphreys (1970), which investigated the social background of men engaging in homosexual behaviour in public toilet facilities, is an example of the way perceptions of what constitutes public (and therefore qualifies as research that can be conducted without obtaining prior informed consent) can be challenged.

In accordance with this perspective is published material in the public domain, where researchers may be exempt from obtaining consent for data collected from television, public records, radio, printed books, conferences or public spaces such as parks. Data from online newsgroups and forums are readily

accessible to anyone, and, if archived, are accessible to the public months or years after messages were posted (Frankel and Siang, 1999). Some researchers interpret cyberspace to be part of the public domain, since the types of web activity they observe are as accessible to anyone as a television or newspaper interview. These researchers believe that the responsibility falls on the disseminators of the messages to filter out what they might consider revealing or private information (Liu, 1999). They adopt the position that this type of research should be exempt from the informed consent requirement, as it is conducted in public and so the requirement is unnecessary.

Due to the lack of public awareness, some commentators/researchers have argued that messages within online communities should not be collected without the author providing prior permission (Marx, 1998; King, 1996). For instance, Egdorf and Rahoi (1994) sought the permission of their computer-mediated communication (CMC) groups prior to conducting research on publicly available lists and archives. The use of such material without the permission of its authors was viewed as potentially damaging to the research process, especially if group members were to discover their words had been used without their knowledge or consent. In these circumstances, participants on discussion forums may feel that their privacy has been invaded and may become distrustful of online groups and of the research community. Wilson and Atkinson (2005) also question whether online ethnography might be a form of 'electronic eavesdropping'. An individual might post information on his or her public profiles to be shared with friends and peers; however, this does not mean that they have consented for this information to be collated, analysed and published, in effect turning them into research subjects (Eysenbach and Till, 2001). Hudson and Bruckman (2004) found that while it might be widely considered ethically acceptable to capture and analyse interactions and conversations in a public square without consent, this model did not match the expectations of their participants in real-time chatrooms, who felt strongly that *"one may not ethically record an otherwise ephemeral medium without consent from participants"* (2004:118).

However, many online studies have been conducted without permission. Fox et al. (2005) engaged in web research that involved scrutinising the content of open-access discussion forums without the express permission of the website moderator or the contributing parties. Furthermore, Eysenbach and Till (2001)

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have contended that it is ethical to record activities in a public place without consent provided individuals are not identifiable. Human subject research norms such as informed consent do not apply to material that is published. However, the nature of online content means that it is more complex to distinguish between published and non-published material (Bruckman, 2004:103). Rees and White (2012) also conducted documentary analysis, viewing their online data the same as any other publicly available text, in their study of forums discussing rape prevention. Meanwhile, Hewson et al. (2003) argue that:

*“If confidentiality is ensured, and given that authors publish such documents with the knowledge that they are publicly available, we do not consider this approach to raise any serious ethical problems, though this statement is bound to raise controversy”* (Hewson et al., 2003:40).

Furthermore, Garton (1997) claims that researchers are *“only participating in the electronic equivalent of hanging-out on street corners...where they would never think of wearing large signs identifying themselves as ‘Researcher’”*. Posts to email forums have also been recorded and stored without consent in a number of studies (Finn and Lavitt, 1994; Reid, 1996).

What is public and what is private is blurred on the Web. It is not sufficient simply to rely on whether a site is public or not; privacy and confidentiality are further important considerations for online research. These issues will now be discussed in more detail.

### **4.5.8. Privacy and Confidentiality**

Ethical guidelines for social researchers state that the privacy and confidentiality of participants must be upheld during the research process (American Psychological Association, 1992; British Psychological Society, 1993, 1995; British Sociological Association, 1993). Privacy is a subjective concept; it is impossible to give it an all-encompassing definition or application, and the concept is especially problematic in web research, as Palen and Dourish (2003) have highlighted.

In online environments that are publicly viewable, such as social media and discussion groups, individuals' expectations may be different from in

communications offline, or in private digital correspondence such as email (Smith, Dinev and Xu, 2011). It is not always possible to determine whether users are aware of the public status of their contributions from the contributions themselves, or whether interaction with the user is required. Furthermore, interaction itself could be an infringement of users' privacy rights, as I found in my research within the forums.

Individual and cultural definitions and expectations of privacy are ambiguous, contested and changing. People may operate in public spaces but maintain strong perceptions or expectations of privacy. Frankel and Siang (1999) highlight the *"blurred distinction between public and private domains"* (Frankel and Siang, 1999:1-2) and have suggested that people may be more open online due to a false or exaggerated expectation of privacy (Frankel and Siang, 1999:6). They describe two possible perspectives that may be adopted when delineating private boundaries online. First, a technological perspective assesses the privacy of data files on the Web in terms of their accessibility. Secondly, a psychological perspective considers how the providers of the data may regard the information. A combined approach would *"develop a technological understanding of the issue and then [expand] this understanding to include the psychological perspective of the participants"* (Frankel and Siang, 1999:11).

Other groups have attempted to clarify the boundaries of public data for research (Sveningsson, 2003; McKee and Porter, 2009). According to the ethical guidelines of the AoIR, public forums can be considered more public than, for example, conversations in a closed chatroom (Ess and AoIR, 2002:5, 7). Hence, *"the greater the acknowledged publicity of the venue, the less obligation there may be to protect individual privacy, confidentiality, right to informed consent, etc."* (Ess and AoIR, 2002:5), while Basset and O'Riordan (2002) state that the lacking of applicability of a private sphere implies that all discourse lies de facto in the public sphere. However, Bakadjieva and Feenberg (2001) offer a different perspective, suggesting that the type of research and corresponding forms of relationship between the researcher and the subject has an impact on whether or not a space should be considered public or private.

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Online researchers have accepted that there are certain expectations of a degree of privacy by Web users. Though conversations may occur in public spaces, the content could be private. In such circumstances, people may accidentally disclose personal information that could identify them in the research. As noted in the 2002 version of the AOIR ethics guidelines, privacy is a concept that must include a consideration of expectations and consensus. When conducting research within such shifting terrains, when there is no consensus, or even assumption of consensus, the AOIR suggest that Nissenbaum's concept of contextual integrity (2011) is a valuable construct. Nissenbaum further points out that, in mediated contexts, "*what people care most about is not simply restricting the flow of information but ensuring that it flows appropriately*" (2011:2). The accessibility of online discussions may suggest that they are freely available in a public arena; however, some researchers question whether the availability of information on the Web necessarily makes this information public. For example, Heath et al. (1999, cited in Grinyer, 2007:2) suggest that research involving 'lurking' encroaches on privacy and creates an unequal power relationship. The recent Facebook study<sup>64</sup> provides an example of the way people can feel that their trust and privacy have been violated, even though they are aware that their information may be monitored.

The discussion above has identified that establishing the privacy expectations of research subjects is a problematic issue and one that is intensified by the Web, as is the possibility of intruding on private exchanges and risking personal information during online research. One way to protect privacy is anonymisation. Anonymising data is a process designed to protect research subjects and their personal information, and to satisfy legal requirements such as the DPA 1998. However, whether data can be appropriately or completely anonymised is also debatable in Web research, as I will now argue.

### **4.5.9. Anonymity**

A central feature of research is to provide descriptions and explanations that are publicly available and accessible. One potentially harmful outcome of research, however, is the risk of disclosing an individual's identity, and it is the

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<sup>64</sup> <http://www.cnet.com/uk/news/after-psych-study-facebooks-mood-shows-disconnect/>



responsibility of the researcher to employ preventative measures such as anonymity (SRA, 2003:38-9) where there may be negative effects from disclosure. Although complete anonymity may be difficult to ensure, it is advised to remove all identifying data prior to publication, and where an individual is identifiable, explicit consent is required before publication (Wiles, 2013). However, Web research complicates attempts to ensure anonymity, as data can be easily put into a search engine and the initial source easily discovered.

Bruckman (2002) proposes guidelines that incorporate a “*continuum of possibilities*” in the level of disguise required for individuals’ names when reporting research (Bruckman, 2002:229). The British Sociological Association also advises “*err[ing] on the side of caution*” (BSA, 2002:5) with respect to Web data; steps should be taken to protect all the individuals participating in research by removing all names and any identifying information in the final thesis and in any stored data. URLs or “links” to the forum websites should not be provided, and other personal details should be disguised; however, quotes may be used to evidence any findings and ensure traceability. Bruckman (2002:229) suggests adopting a “*moderate disguise*”, whereby verbatim quotations may be used but names, pseudonyms and identifiable details changed. This approach was also adopted in Hookway's (2008) study of morality in everyday life, where he prioritised the protection of his participants' identity over providing credit to them as authors.

Some online discussions contain personal information. The blurring of the private and public distinction further complicates this. The ethical guidelines of the Association of Internet Researchers (AoIR) suggests a setting-dependent approach to distinguishing between subjects and authors, distinguishing between “*reasonably secure domains for private exchanges*” such as chatrooms and “*public webpages such as homepages, Web logs [i.e. blogs]*” (Ess and AoIR, 2002:7). Where the research context is placed on the public/private continuum, this has an impact on the need to anonymise data. If people are considered to be subjects, then they need to be afforded the protection of anonymity; however, if the information they have posted is considered to be published, then they should be credited as an author. Negotiating these positions is complex, especially if there is no interaction with the researcher, who is left to interpret this quandary.

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Acknowledging when anonymity should be used and when it is necessary to cite a Web user by their name (or pseudonym) is problematic. There may be circumstances when some Web users may not want to remain anonymous, for example writers of blogs (though these appear quite distinct from forum posts), and so it would be inappropriate to anonymise such individuals. This would be viewed as infringement of copyright and incur issues of intellectual property. If Web users are treated as authors of public documents, then issues of ownership of material must be considered. Web users may have chosen to deliberately publish in the public domain. Bassett and O’Riordan (2002:244) argue that in such cases, rather than maintaining anonymity, researchers should acknowledge the user’s authorship and cite their texts as they would more traditional media, but as Ess (2006) points out, this may compromise their anonymity.

Removing all identifying data about the Web user, site etc. prior to publication is one solution to the problem of anonymisation procedures. However, the use of verbatim quotes to substantiate findings can impair this, as the quotes can be traced back to the original website and potentially to the person who made them. This is a new challenge created by the Web, and one that researchers should be mindful of, possibly making the checks to determine the risk of uncovering individual identities. If protection cannot be ensured via anonymity, then perhaps such data should not be reported.

Anonymity per se cannot be solely relied on to avoid the need for informed consent; along with the notions of privacy and confidentiality, it requires intense consideration specific to the research issue and setting, as well as to the individuals concerned.

Having outlined the ethical issues and debate; this chapter will now address the way these have applied to my research.

### **4.5.10 Conducting Ethical Online Research in my Studies**

I found myself constantly having to defend the ethics and my role in the research process. During my research, the key issues of informed consent, privacy and anonymity previously discussed were highly significant, as was the blurring of the public and the private in the online words I studied.

#### 4.5.10.1. The Public/Private Tensions within my Research

I tried obtaining informed consent for the observational study, but ended up treating the forums as public data and adopted the role of 'lurker'. For the survey and interviews, I obtained informed consent but still struggled with issues of privacy and confidentiality.

The analysis of the posts demonstrated that Goffman's (1957) ideas of front and back stage play out in forums. In online communities, there are back regions clearly divided from the public fronts, so that only members have access to the private areas of web forums. I chose to look only at public areas of the Web, but nonetheless it was clear that the boundaries between private and public spaces are often blurred and permeable. People appeared to forget how visible the public spaces were, posting information that was not necessarily meant for others outside of the forum community.

My research on Web forums suggested that people may be far less careful about how they present and perform online. Despite being in the "public" domain, some people posted things that appeared private. In the context of medicines, forum members talked about disobeying regulation and purchasing "banned" medicines. This problem of what is public and what is private was not only a problem for forum users. I also found it was a serious problem for me. This was brought home to me when I tried to be public about my research. My joining of the forums caused the boundaries of perception of what is public and private to be blurred. These were not private spaces, yet in joining I caused the members to act as if they were private, thus upsetting the balance. I was potentially seeking affirmative responses when there was no actual need to do so. Williams (2006) claimed that online communities adopt the use of ostracising methods to restore order. In my study, the members informally regulated the forums with their public retaliations and ridicule of me. As Wall and Williams (2007:393) claim, "*online communities have developed their own distinct history of control and regulation*". Miller et al. (2012) consider the question of what protection is afforded to the researcher when participants respond in public forums. My research practices appeared to occupy a space beyond the reach of ethics frameworks, professional ethics guidelines and (pre-study) ethics review and governance; I was in uncharted territory.

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Attempting to be more ethical seemed to create more problems; people did not want to be alerted to any intrusion. In contrast, looking at the data without openly announcing that I was doing so appeared easier. The covert approach enables research to be undertaken without risk or harm to the community, especially where a posted site policy notifies users of its public access, which is a point noted by Sveningsson (2004).

The tension between the public and the private was also apparent in the responses to the survey. Survey respondents seemed to be more aware of their actions being in the public domain and were more careful with their disclosures than the forum members, who openly discussed potentially deviant behaviours. Perceptions of what is public and what is private undoubtedly encouraged different accounts.

However, the responses in the interviews indicate that participants viewed this type of research as being private. As Israel (2004) notes, such assumptions are especially important in circumstances where participants are asked to reveal information related to criminal activity or other potentially socially sensitive experiences. In Chapter six, I will discuss how some participants admitted to behaviours in the interview that they had not disclosed in the survey. I have identified an interesting tension between the public and the private, both in people's accounts and in my research about the purchasing medicine online. I have suggested that Goffman's work can aid our understanding of the way people manage and present their behaviour online. His theory of the presentation of self tells us that people undertake impression management in order to ensure that a positive self-image is portrayed to others. However, on the Web, people sometimes do not seem to realise that the public and private boundaries are blurred. People do not manage their "selves" in forums, but do when they are researched. This creates new challenges and ideas for online research.

### **4.5.11. Navigating the Ethical Problems**

In this section, I will reflect upon the way I navigated through these ethical issues.

Although I viewed the forum data as public, for the collection purposes, merely treating it as public text used for documentary analysis was insufficient, as I

had to consider the thoughts and intentions of those who had produced the information. Examination of people's feelings about that situation – the ethic of reciprocity, or Golden Rule, where the researcher considers how they would feel if the roles were reversed - was considered, in order to appreciate how those observed might respond to the research (Honderich, 1995; Rawls, 1958). I investigated the extent that forum users felt that they were talking verbally but via the medium of typing and whether the data was regarded as ephemeral as was spoken conversation. This had an impact on whether the environment was considered public or private; for example, if someone was talking in a public space, it was reasonable to expect that their conversation could be heard and accessed by others. However, this was difficult online, as Web spaces have ostensible boundaries. Content on websites can be accessed by anyone and is not necessarily meant for public consumption. However, I familiarised myself with the place I was studying in order to ascertain whether it should be considered public from the perspective of those who occupied it. This required continual reflection during the research process.

When quoting comments, anonymisation was fundamental, as negative consequences to participants could arise from disclosure that resulted in violation of privacy. Even though the information was readily available to anyone online, and could be found by anyone using the same search terms as me, I did not want to bring any extra unnecessary attention to anything that had been written in cyberspace by individuals, especially where it had been analysed in relation to this particular research issue. Therefore, anything of an embarrassing or sensitive nature, such as information about personal illnesses or weight, was removed and not used within my forum data.

It is evident that simply trying to apply traditional ethics to online research does not work well in practice, and actually has the potential to create an unethical situation. Although traditional ethical considerations do apply online, they should be deliberated and applied in a Web context. Individuals and their online privacy expectations should be respected. If an individual has posted information on a public website under a public 'privacy' setting, they may be considered to have a very low or no expectation of privacy for the information they reveal; regardless, in such situations the researcher needs to be careful not to make undue assumptions. However, researchers who collect and analyse such information should take care to protect it from becoming identifiable to

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individuals. As such, conversations should not be copied verbatim into research publications, as those direct quotes can be searched and identities discovered. A small number of relevant conversations can be summarised without losing character in reports. The jury is still undecided over whether full quotations need permission, though the various principles of ethics that have been discussed would suggest that this is more likely the case.

No single, monolithic ethical code can be applied to online research. It is only possible to frame an ethical position on the particular research questions and methodology used. However, what this experience has highlighted is the importance of continual ethical consideration during the research process. Ethical considerations do not stop once ethical approval has been obtained from the institution's ethics committee/IRB/RGO. It is an ongoing process, requiring constant reflexivity on the part of the researcher. During each step of the study, the researcher should continually ask themselves if they are remaining ethical and keep considering the thoughts and feelings of those whose data is being studied. For instance, though there was no disturbance caused to forum members whose publicly available posts were retrospectively scraped in my study, upon analysing the data it became clear that some subjects were personal or embarrassing. Therefore, even though the information was historic, the content was something that had to be protected, as publishing it in its entirety would have been detrimental to the individual. In such circumstances, I chose to omit the information from the data used in the thesis. Though posts were easily discoverable via search engines, drawing extra attention to them by publishing them verbatim would have been unethical.

It might be valuable to adopt a "consequentialist approach", where the research could be determined to be for the "greater good" of society. Ethical decisions should be based on the consequences of specific actions, thus an action is morally right if it produces a good outcome for the wider society. The aim of my research was to obtain information that addresses a societal issue that has profound public health concerns. There was no deception involved; I did not lie to participants, and in the case of the forums, there was no provable/measurable harm caused to any individual by using their publicly available data. Waskul (1996:6) highlighted the importance of balancing "*the needs of the research with that of the research subjects*".

I struggled to navigate ethics because of a lack of appropriate guidance and controversy over the best course of action. When I tried to follow the 'rules', it backfired, so I had to reassess my methods and utilise other approaches. My research has shown that people do not always think about the public status of their actions and conversations online, and that obtaining informed consent is practically difficult and possibly leads to bias.

The position that I adopted is one of a middle stance, between the overly-rigid practices of ethics sometimes adopted in academic research, and the laissez-faire attitude taken by some forms of journalism and in large-scale research organisations. The need for beneficial ethical consideration was acknowledged and administered, but ethical approaches were not employed to the extent that they became too restrictive and limiting to the research. Although disciplinary and institutional guidelines were followed, it was important to consider my natural instincts as well as the context of the research environment.

#### **4.6. Summary**

This chapter has outlined the design of the study and justified the chosen methodological approach. I have shown how I have designed a mixed methods study comprising of three sequential phases. The chapter has discussed the challenges surrounding the notion of online ethnography and different online and offline forms of data collection. Overall the data analysed was 213 forum posts, 240 survey responses, and 28 interviews.

One of the specific issues I faced was with the sampling and representativeness, especially in relation to the forum and survey data. Regarding the forums, I could only work with the data publicly available. This meant that I was only accessing the views of certain online medicine consumers. Similarly with the online survey, there was an over representation of well-educated, UK respondents. However, my target population did not include those not connected to the Web, and my sample did only consist of web users. As this research was driven by an interpretivist paradigm, the focus was on meanings and understandings rather than representative populations and generalising the data.

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This chapter has also addressed the key ethical considerations when undertaking online research. I have discussed the blurring distinction between public and private Web spaces, whether or not obtaining informed consent in public spaces is necessary, maintaining privacy and confidentiality and the significance of anonymity.

In the next chapter, I will use the findings from the forum and survey analyses to show the routes to online medicine purchasing, the types of medicine that are available on the Web and the types of websites that are selling them, as well as who is the online medicine consumer, in order to provide insight into the way people are purchasing medicine online.



## **5. Findings: Purchasing Medicine Online as New Opportunities**

*When you start looking and see what's on there, it's like everything is on there [Fiona F7].*

This chapter considers the initial theme of opportunities in online medicine purchasing. It uses data obtained from the forum, survey and interview studies to answer the following research questions: 1. *What are the different routes for purchasing medicines from the Web* 2. *What types of medicine are available online and what types of websites sell these medicines?* 3. *Who is purchasing medicine online?*

The chapter begins with a discussion about the demographics of the online medicine purchaser and consider whether gender or age affect purchasing. The chapter then looks at how people find out about online pharmacies and where people usually obtain their medicines. Purchasing behaviour, which distinguishes between those who admit to purchasing medicine online and those who say they have not, is then considered. This provides some context as to who is purchasing medicine online and some understanding of the numbers of online medicine consumers. The chapter then turns to how often medicine is purchased online, and the theme of normalisation is considered in the context of online medicine purchasing as part of everyday consumerism. Furthermore, qualitative and quantitative data are used to explore legitimate and illegitimate means of procuring medicine online. These findings address the routes to online medicine purchasing.

The chapter then concludes with the types of medicine that are available to purchase online, along with the types of websites that are selling them. However, as the discussion that follows will highlight, the indication is that people are not always forthcoming with the truth when it comes to online medicine purchasing.

## **5.1. Demographics**

The survey provides information about individuals who are reportedly online consumers of medicine, in total, 240 respondents completed the survey. Table 6 displays a breakdown of the demographic information. There was a good spread of age groups, but there were more females than males. This may reflect bias in the way the survey was administered, namely via existing social networks and forums that discuss topics that may be more female-centric. Residents from the UK and those of a British background were also over-represented, as might be anticipated in research located in the UK. Respondents were typically employed and had a high standard of education, which may be a result of sampling from the MOOC. The literature suggested that the typical online medicine consumer is someone well educated from a higher socio-economic status (Littlejohn et al. 2005) so the data might represent this, however, without having a wider sample to compare, this notion cannot be challenged or supported.

In my sample the over half of respondents were working, whether employed (46%) or self-employed (13%). Again, if the data were representative this might have corresponded with Littlejohn et al (2005), who claimed that those in employment would be more likely to use an online pharmacy, due to having twice as much access to the Web. Although, this does not take into account the growing numbers of web users, for example 38 million UK users accessing the web every day that were identified by the ONS (2014).

Table 6 Characteristics of survey respondents

	<b>Variable</b>	<b>Sample</b>	<b>Percentage</b>
<b>Age</b>	18-24	26	11%
	25-34	53	22%
	35-44	48	20%
	45-54	50	21%
	55-64	42	18%
	>65	18	8%
<b>Gender</b>	Male	102	43%
	Female	127	53%
	Prefer not to say	5	2%
<b>Location</b>	United Kingdom	174	73%
	Outside the United Kingdom	63	26%
<b>Employment Status</b>	Employed	111	46%
	Self-Employed	30	13%
	Out of work and looking for work	20	8%
	Homemaker	4	2%
	Student	27	11%
	Retired	28	12%
	Unable to work	7	3%
	Prefer not to say	5	2%
<b>Highest Educational Qualification</b>	Level 2: 5 GCSEs or equivalent	11	5%
	Level 3: 2 or more A levels or equivalent	27	11%
	Level 4 or above: Bachelors degree or equivalent	171	71%
	Other qualifications including foreign qualifications	16	7%
	Prefer not to say	5	2%

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Information about the purchasing groups ('purchasers' and 'non-purchasers') was broken down further by looking at other demographic variables. In the first instance gender was compared to see whether more women than men, or vice versa, purchased medicine from the Web. More women took part in the survey overall and a larger proportion of women claimed that they did not buy medicine online, but these do not seem to be statistically significant differences in purchasing behaviour. Aside from Atkinson et al. (2009) who claimed that women aged 35-74 were more likely to purchase medicine online, gender as a precursor to buying medicine from the Web, has not been focused on in the literature. My study indicates that there is indeed no distinction and both men and women are just as likely to buy medicine online. Table 7 shows purchasing by gender.

Table 7 'Have you ever bought medicine online?' by gender

Gender	Have you ever bought medicine online?			
	Yes	No	Non-Disclosure	All
Men	22 (22%)	60 (59%)	20 (20%)	102 (44%)
	25 (20%)	90 (71%)	12 (9.%)	127 (54%)
Women	0	4 (80%)	2 (40%)	5 (2%)
Prefer not to say	47 (20%)	154 (66%)	33 (14%)	234
Total				

Turning to the data on age groups (Table 8), the numbers of those who buy medicine from the Web are distributed across all age groups. However, when we take into consideration the numbers of respondents in each age group we can see some minor differences; for example, the largest age group is that of 25-34 year olds, but this group has one of the smallest numbers of purchasers. On the surface this is interesting because this age group made up the largest amount of web users in 2014, with 28 % of global web users aged between 25-

34 years old.<sup>65</sup> Although it is unsurprising that this age group is the largest within the sample, it is perhaps unexpected that a greater group, both in terms of my survey and overall web use, appears to not be purchasing medicine as much as other age groups. However, if we turn to the 18-24 group, they have a much larger number of purchasers, and constituted the second largest age group of global web use in 2014 (27%) (Statistica, 2014), which seems more consistent. The over 65 group also indicated that a larger number within their sample purchased medicine online. The literature suggested that online market vendors use targeted advertising, especially towards specific age groups such as adolescents and seniors (Liang & Mackey, 2009). This is because they are viewed as more vulnerable and potentially more likely to buy medicine from the Web. If age is a determinant of online medicine purchasing, potential explanations may be that such individuals are responding to the marketing campaigns, or that online vendors are accurate in their predictions. However, further analysis challenges such notions.

Table 8 'Have you ever bought medicine online?' by age

Age	Have you ever bought medicine online?			
	Yes	No	Non-Disclosure	All
18-24	9 (35%)	14 (54%)	3 (12%)	26 (11%)
25-34	7 (13%)	38 (71%)	8 (15%)	53 (22%)
35-44	8 (16%)	36 (75%)	4 (8%)	48 (20%)
45-54	11 (22%)	32 (64%)	7 (14%)	50 (21%)
55-64	7 (17%)	27 (64%)	8 (19%)	42 (18%)
>65	6 (33%)	8 (44%)	4 (22%)	18 (8%)
Total	48 (20%)	155 (65%)	34 (14%)	237

To examine the possibility that age might predict online purchasing, I collapsed the three youngest and the three oldest age categories, and tested

<sup>65</sup> <http://www.statista.com/statistics/272365/age-distribution-of-internet-users-worldwide/>

differences in purchasing behaviour. A chi-square test was used to determine whether age was a significant determinant of purchasing.

Figure 6 Chi-square examining age and purchasing habits

	Web Purchaser	Non-Web Purchaser
Group 1	24	88
Group 2	24	67

Using a Fisher’s exact test on a two-tailed hypothesis, it was found that there were no significant differences between the two groups (p-value = .41). Group 1 and Group 2 were not different; therefore, age was not a determinant of online medicine purchasing.

The ‘identity’ of the online medicine consumer in relation to their motivations and perceptions, will be further explored in the next chapter. This will provide a greater understanding of who is purchasing medicine online.

The chapter now turns to how people are purchasing medicine online, starting with how they initially discover the availability of medicine to buy from the Web.

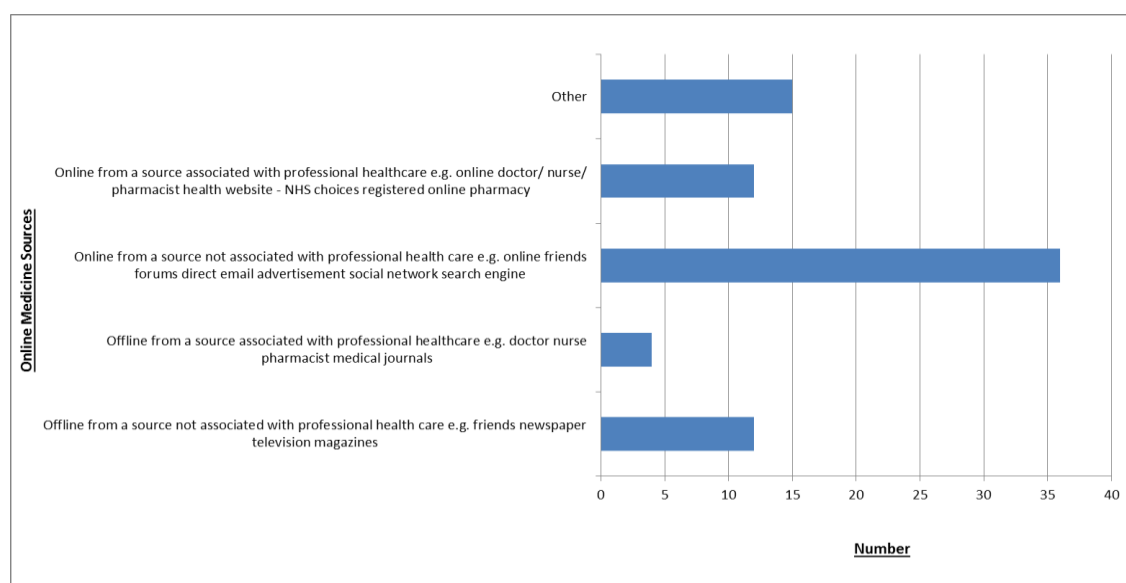
## **5.2. Finding Out about Online Pharmacies**

The initial question on the survey asked whether respondents had ever bought medicine online. 49 respondents identified themselves as purchasers (P) of medicine from the Web (20%); 156 people said they had not bought medicine from the Web and were hence identified as non-purchasers (NP) (65%). A further 35 respondents did not disclose whether they had bought medicine online (and were referred to as ND) (15%). Existing research suggests that online medicine purchasing is a growing phenomenon due to the ever-increasing amounts of both legitimate and illegitimate websites selling medicines; however, it is difficult to quantify the numbers of people who are engaged in the purchasing. Although there are numbers regarding visits to

online pharmacies, there are limited figures for purchases from registered online pharmacies (Fox, 2004; Baker et al., 2003; Cohen and Stussman, 2009; RPS, 2008) and naturally it is impractical to uncover consumer statistics from unscrupulous online medicine vendors. However, the overwhelming majority of respondents in my survey stated that they had never bought medicine from the Web. This challenges Gurau (2005) whereby a third of the respondents in that study had bought prescription medicine over the Web, or were intending to do so. However, as I will demonstrate in later discussions, this finding is complicated by further analysis uncovering inconsistencies in accounts of online medicine purchasing that require more consideration and explanation.

Respondents in the survey who said they had purchased medicine online were asked where they had heard about purchasing medicine online, in order to investigate online medicine purchasing pathways. Respondents were able to tick several responses from a predefined list of sources that they felt applied to them. The answers indicated that knowledge of online purchasing is first obtained from the Web itself. By providing information and knowledge, the Web itself is a route to medicine purchasing; however, the main online sources that people find out about medicine online are not identified as associated with professional healthcare. Online communities and searches may provide information of questionable quality (Eysenbach et al., 2002) and could direct people to dubious websites. Only 15 respondents said that they had learnt about online medicine purchasing offline.

Figure 7 'Where did you hear about purchasing medicine online?'



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Respondents were invited to provide further elaborations in qualitative responses on the survey. Qualitative data from open-ended questions are indicated by the letter S for survey, either the letters NP (non-purchaser) or P (purchaser) and a number representing each respondent. For example, the first qualitative response from a survey respondent, who had ticked that they have purchased medicine online, would be presented like this - SP1.

Nine respondents provided lengthier explanations. Five of these referenced Google and web searches, and two indicated that they had discovered opportunities to buy medicine online during other web-related searches:

*I simply googled the medicine I wanted to check its price and then found to my surprise that it was available to buy online [SP1]*

In accordance with Peterson et al.'s (2003) study, other consumers appeared more knowledgeable from the outset, and deliberately searched for online pharmacies.

*Google search for UK providers of the medicine [SP2]*

Some consumers indicated that they needed a particular medicine, which they were unable to obtain via other means:

*Drug prescribed abroad by a doctor but not available (NICE) in UK. Searched web for source AND with my GP's consent bought them. ONE OFF OCCASION [SP3]*

This apparent medical 'approval' for online purchasing is a theme to which I will return in the next chapter. Having presented the survey data in relation to the routes to online medicine purchasing, I will now discuss the forum data.

The forum data allow us to explore in more detail some of the aspects of online purchasing described by the survey analysis. Having read and coded the data, my interpretation of the general overview and tone of each of the forums is summarised as follows:

- Forum 1: members talk about avoiding doctors due to reasons of embarrassment, and cost is a significant factor when using the Web to buy medicine.



- Forum 2: members' conversations concern the risks associated with buying medicine online.
- Forum 3: members have mixed views and talk about both positive and negative experiences. They appear concerned with cost and the effectiveness of medicines.
- Forum 4: there is the suggestion that members in this community are challenging authority with their attitudes and their negative experiences with healthcare are driving them to the Web.
- Forum 5: members are concerned with efficacy, and there is an over-representation of lifestyle aesthetic medicines. There is the suggestion that members knowingly want to order prescription and banned medicines.

The data are presented as neutral IDs (for example F1 = Forum 1, F1 member a) to preserve anonymity. As the discussion on ethics in the previous chapter highlighted, online data obtained without informed consent needs to be treated with caution, and so in the forum data that follows company names and/or specific types of medicine have been omitted in order to prevent the quotations being used to trace back to the original sources via search engines. However, enough of the original posts are used to provide a flavour of the conversations and accounts and substantiate my analysis.

In accordance with the literature suggesting that peer influence plays a part in online medicine purchasing (Cordaro et al, 2011, Eysenbach, 2001a) forum members made recommendations for sites selling particular medicines.

*Found this forum when I was searching on Google, so have decided to join! Not sure if people are still struggling but I have found some here.  
[F4 member i]*

Amongst the online searches for a particular type of medicine, this person found both an outlet to purchase said medicine and a community to share this discovery with. This particular post contributed to a thread specifically dedicated to the medicine in question.

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Indeed, much of the conversation was useful to people researching this medicine online, and fostered the discovery of forums and communities discussing healthcare. Actively seeking information about the availability of certain medicines and other's experiences with purchasing medicine online was a recurrent theme within the forums, as these quotations illustrate:

*I was taken off it by my new Drs and now find it very hard to get...despite changing Drs. I am thinking of buying some on-line does anyone else do this? [F3 member b]*

*Hi - Does anyone know where I can order tablets from? I have searched the web but am not having much success. Thanks! [F5 member b]*

In the first quotation the member has turned to the Web and the advice of their forum community due to dissatisfaction with how they have been treated by healthcare professionals. Menon et al. (2008) spoke about the advent of 'medical consumerism' where consumers can challenge the paternalism of healthcare professionals via the wealth of healthcare information and opportunities online. Whereas pre-web the matter might have been left, the patient would not have been able to resource and purchase the medicine (without resorting to the illegal drugs trade); nowadays the Web provides other options in affording knowledge, support and new consumerist choices.

I have shown how the Web creates opportunities to discuss, obtain and disseminate medical knowledge amongst a virtual community. Using the Web for healthcare purposes or to find information about medicines is commonplace (Caruso, 1997; Eysenbach et al., 2002; Menon et al., 2008; Peterson et al., 2003). The conversations in the forums indicated that some members were keen to resource the information and purchase online, viewing the Web as a 'one stop shop' for their healthcare needs. In some of the forums there were posts with links to websites selling medicines associated with the counterfeit and illegitimate pharmaceutical trades, such as lifestyle medicines like steroids and slimming pills. These were often accompanied by brief messages expressing satisfaction with their efficacy and cost. Although I removed posts that only contained links and no text suspecting that these were spam, other posts might also have been direct advertising . In the examples below I have removed the links and assigned the websites mentioned IDs.

*Both of these drugs work perfectly! I have tried both, but is more cheaper and has the same effect website 6. You can order online jelly and the pill form, whatever you like [F1 member b]*

*I get genuine pills online on website7 it's a site that ships directly from UK so I never had any problems in receiving my order fast and safe. Besides the package is discreet and comes to my doorstep. The pills are effective and fresh so I do recommend to everyone. [F5 member d]*

Searching for medicine and/ or health information online peer influence are main routes to online medicine purchasing. Some forum members who discuss online medicine purchasing, knew the specific type of medicines they wanted before using the Web, and so undertook searches online (Menon et al, 2008) that searches led them to the forums and websites selling the medicine. The community spaces of the Web, enable opportunities for the dissemination of information about how and where to buy medicine online. Forum members share their knowledge and experiences and can make enquiries as to where to buy online. As such the Web is a tool to draw people into the community and a place to conduct virtual negotiations (Markham, 1998, 2003, 2007).

Burrows et al. (2000) described the use of the Web for online self-help and support as 'virtual community care'. The forum members provided a similar virtual community, sharing knowledge about how to navigate the Web. This included information about how to bypass the healthcare system.

*I've been ordering for over a year now, great products and reliable service. Speak to a guy called Jay. [F1 member a]*

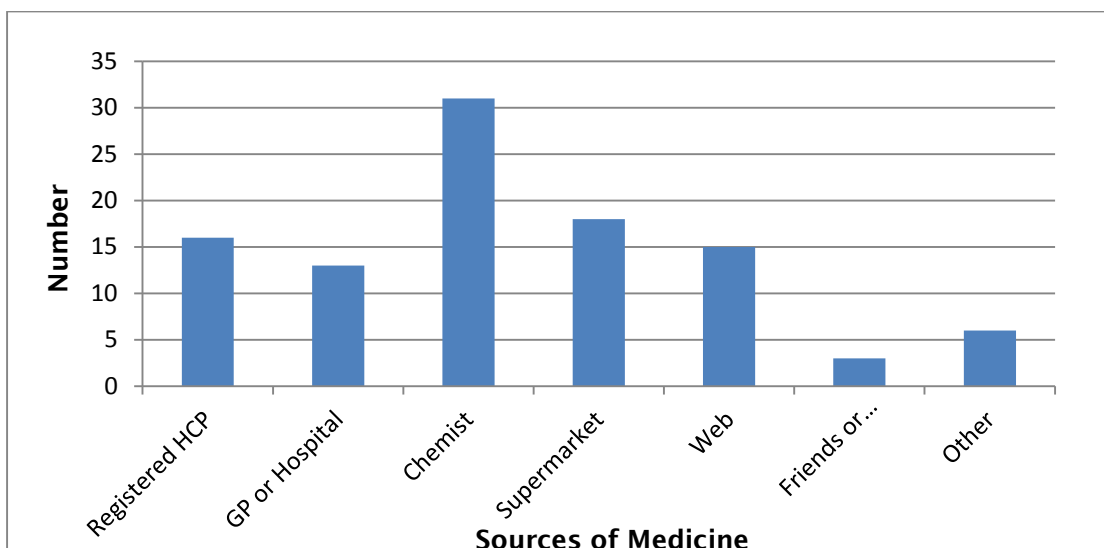
*I have been on these tablets for about one year and in that time I have lost well. I received the order and it was on time and the pills work great. [F5 member a]*

The chapter now turns to the survey data to explore where people typically obtain medicines in order to contextualise the extent of online medicine purchasing.

### 5.3. Where do Respondents Usually Obtain Medicines?

The survey asked where respondents usually obtained medicines. The focus on online purchasers would indicate that although they have used the Web to obtain medicine, it is not necessarily the only source used (see Figure 8).

Figure 8 'Where do you usually obtain medicines?' (Purchasers)



Purchasers favoured the chemist and the supermarket; compared to these, the Web is less preferred for usual purchases. Without knowing whether the medicines required prescriptions or no, this could be due to the fact that people are purchasing OTC or medicines that can be bought ‘off the shelf’ on a more frequent basis. Such medicines are more the day-to-day treatments that can be easily picked up when grocery shopping. Although, of course if, as my data has been suggesting, more and more people are turning to the Web to conduct their shopping, then perhaps medicine will become a more prominent feature within that consumption too. As I will go on to show in the remainder of this chapter, these types of medicine did feature across the data. In the next chapter I will also discuss how some interviewees were keen to emphasise that they only purchased medicine online that did not require prescription. However, there was confusion about the classification of medicines, which meant that some medicines were prescription medicine, in the countries where the interviewees were based. The accounts suggested that interviewees wanted to present themselves as adhering to regulation, or if they actually were aware of the regulatory status, of trying to mislead the situation for some other purpose.

It is also interesting that the Web received nearly as many responses as registered health care professionals, separate from chemists, as a usual place to obtain medicine. However, this data does not ascertain whether consumers interacted with a doctor or healthcare professional before purchasing online. Nevertheless, with the Web becoming a more popular outlet to obtain medicine, healthcare expertise is challenged and consultations perhaps unnecessary (George, 2006). Expertise is a key theme, which I return to in the next chapter.

To further compare the different purchasing groups, a cross-tabulation of 'Have you ever bought medicine online?' with 'Where did you last obtain medicine?' was undertaken (Table 9).

Table 9 'Where did you last obtain medicine?' \* 'Have you ever bought medicine online?' cross-tabulation

Where did you last obtain medicine?	Have you ever bought medicine online?			
	Yes	No	Non-Disclosure	All
Doctor/Nurse/Pharmacist at a Hospital	3 (13%)	16 (70%)	4 (17%)	23 (10%)
Doctor/Nurse at a General Practitioner	10 (20%)	34 (67%)	7 (14%)	51 (22%)
Local Pharmacy/Chemist	16 (16%)	76 (75%)	9 (9%)	101 (43%)
Supermarket Pharmacy	5 (21%)	14 (58%)	5 (21%)	24 (10%)
Supermarket Shelves	4 (31%)	8 (62%)	1 (8%)	13 (5%)
Web/Online Pharmacy	9 (56%)	2 (13%)	5 (31%)	16 (7%)
Other	1 (11%)	5 (56%)	3 (33%)	9 (4%)
Total	48 (20%)	155 (65%)	34 (14%)	237

This cross-tabulation alerted me to an inconsistency in the data: two positive responses about web/online pharmacy purchases from respondents who had also said that they had never bought medicine online. In addition, five

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respondents from the non-disclosure group revealed in this question that the last place they obtained medicine from was the Web. To check these anomalies, I cross-tabulated 'Have you ever bought medicine online?' with 'the Web/online pharmacy' as a route for 'usually obtaining medicine' (see Table 10).

Table 10 'Have you ever bought medicine online?' \* 'Web/ online pharmacy' cross tabulation

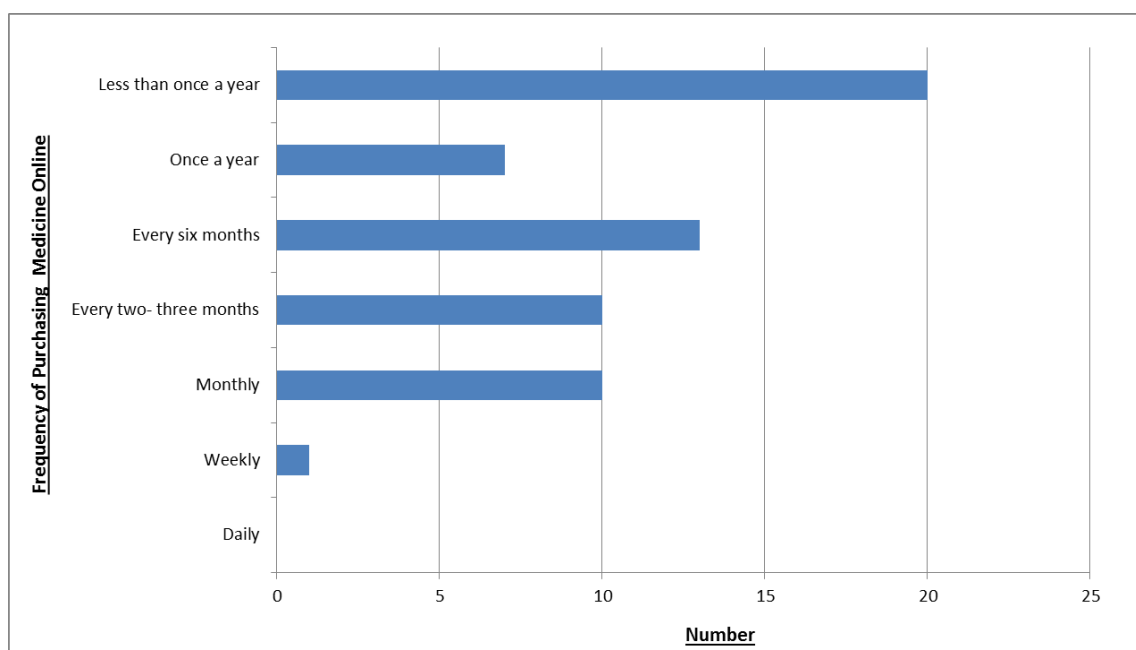
Have you ever bought medicine online?	Usually buy from the Web/online pharmacy		
	Yes	No	All
Yes	15 (31%)	34 (69%)	49 (20%)
No	5 (3%)	151 (97%)	156 (65%)
Non-Disclosure	8 (23%)	27 (77%)	35 (15%)
Total	28 (12%)	212 (88%)	240

Five 'non-purchasers' reported the Web as a place from which they usually buy medicine, contradicting their earlier answer. This will be explored further in the following chapters.

## **5.4. Frequency of online medicine purchasing**

The survey also examined frequency of purchasing medicines; see Figure 9. These answers need to be interpreted cautiously, as they do not measure the quantity of medicines purchased, dosages or medicine strength.

Figure 9 'How often do you buy medicine online?'



The majority of respondents bought medicines less than once a month and few purchased them on a weekly basis. As we do not know the size of the orders or the number of shipments, it is not possible to deduce the actual extent that consumers are using the Web to meet their medicine needs, the quantity of online medicine that is being consumed, or whether they are purchasing purely for themselves or for others too. Lavorgna (2015) evidenced that some online pharmacies distribute large orders into smaller consignments, which can avoid detection from the authorities and appear for personal use.

The interviews delved deeper into online medicine purchasing and investigated the accounts that people provide about this activity. Interviewees elaborated on how often they bought medicine from the Web. They described how online purchasing was normalised, and how the Web had increased the availability of medicines.

In what follows, the names of the interview participants are disguised to preserve anonymity. Table 11 provides more information about the interviewees, such as whether they have purchased medicine online or not, their location and employment status. Quotations are identified with the pseudonym and method of data collection – E for Email, IM for Instant Messenger, F for Face-to-Face, T for Telephone and S for Skype, and the number of the interview.

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Table 11 Interviewee attributes

<b>Interview Number</b>	<b>Interviewee Pseudonym</b>	<b>Have Purchased Medicine</b>	<b>Location</b>	<b>Employment Status</b>
1	Anne	N	UK	Employed
2	Beth	N	UK	Student
3	Carole	N	UK	Employed
4	Diane	Y	US	Unable to work
5	Esther	Y	UK	Homemaker
6	Anthony	Y	Canada	Student
7	Fiona	Y	UK	Student
8	Gina	N	UK	Employed
9	Ben	N	UK	Employed
10	Holly	N	UK	Employed
11	Carl	Y	UK	Retired
12	Isabelle	Y	UK	Unable to work
13	Julie	Y	UK	Self employed
14	Kay	Y	Outside the UK	Employed
15	David	?	UK	Employed
16	Linda	N	Austria	Employed
17	Marie	Y	UK	Student
18	Nicole	N	Outside the UK	Employed
19	Olivia	Y	UK	Employed
20	Ed	Y	US	Employed
21	Finn	Y	UK	Employed
22	Rosie	Y	UK	Student
23	Greg	N	UK	Employed
24	Sophie	Y	Australia	Employed
25	Tina	Y	Luxembourg	Employed
26	Harvey	N	Austria	Employed
27	Ian	Y	UK	Employed
28	John	Y	UK	Unemployed



Some interviewees who bought medicines from the Web justified online shopping as normal in the context of everyday online consumption. Esther compared her online medicine purchasing with the other sorts of online shopping that she did:

*It's getting more frequent - maybe once every couple of months? I've only done it in the last year, I guess, and it seems like I did it once, then have done it a couple more times recently... probably, it will become like clothes-shopping... [ ]...It's getting more frequent as I get used to buying medicines online. After the first time I shopped online for clothes, I gradually increased my shopping that way, until I was doing more online shopping than real-life shopping. It started out, I think, partly because I had young children and don't drive, and it's now, it's just easier for me to do things from home because I'm used to it. And the more used to shopping from home I get, the more things I'll buy from home [Esther E5].*

Esther also highlighted the ease and convenience of online shopping, which supports the literature on online consumerism (Ahuja et al, 2003; Wolfinbarger & Gilly, 2001). It has been acknowledged that online shopping provides greater freedoms to consumers, distinct from shopping offline, which becomes pervasive within everyday life (Wolfinbarger & Gilly, 2001). Other studies have also associated these online opportunities with online medicine purchasing (George, 2006; Banks et al., 2009). In Esther's own words, she has got *used* to this new means of shopping and it has impacted on the frequency of her purchases.

Other interviewees echoed this theme of normalcy. For Fiona, stories about women buying medicine from the Web in the media helped to make it seem like a *normal* activity:

*I think actually, I remember reading news articles about women buying these things online. SO it was like "wow" everyone is doing it, it was almost a normal thing to do. I think it was because I had read about someone buying the abortion pill online and it was like "my god" you can get anything. It's been over-the-counter stuff though. It's like also when you do supermarket shopping you can include your medicines in that now [Fiona F7].*

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In this case, Fiona had been informed about the availability of medicines to purchase from the Web from media sources. She clarified that she had accessed these news reports online and so the Web was the source of her finding out about purchasing medicine online. Other interviewees provided accounts of their online searches for medicines, where they were not necessarily looking to purchase medicine (especially from the Web) but were requiring information or to discover what treatments are available. In the next section I will further explore the routes to purchasing.

People who stated that they had never purchased medicine from the Web were also interviewed. However, Greg mentioned that while online shopping was normal, this did not extend to buying medicines from the Web.

*I would say that the majority of my shopping is via the Web, but I would not consider getting my medicines online [Greg F23]*

Greg cited a lack of trust in online pharmacies as the main reason for his reluctance towards using the Web to obtain his medicines. According to the Consumer Web Watch (2002) there was a 'lack of trust' in Ecommerce, nevertheless the Web is continuing to grow as a purchasing tool (Cofta, 2006). What is interesting is that those who have not purchased medicine online demonstrate this absence of trust, however, the opposite discourse on trust was not found in the data. This opposes the expectations outlined in the literature discussed in Chapter 2. However, in presenting online medicine purchasing as a normal consumerist action, trust could be automatically assumed. Purchasing medicine online is not distinct from purchasing medicine offline, and is viewed as part of the healthcare routine. It is also possible that there is a distinction between how those that have purchased medicine online as opposed to those that have not, respond to the associated 'risks.' This will be explored further in the next chapter.

The interviews suggest that the Web itself is a main source for finding out about the availability of medicine to buy online. The data has demonstrated that people talk about the purchasing of medicine online in relation to other consumerist behaviour on and offline. People who purchase medicine online are doing so on a more constant basis as they view it as part of 'normal' shopping activities. Their medicine purchases increase as they become further accustomed with everyday online consumption.

As the exploration of the literature highlighted, the challenges and risks associated with online medicine purchasing become more prevalent when the action is illegitimate or illegal. The chapter now turns to data exploring whether people are able to differentiate between illegitimate and legitimate online medicine purchasing, to further inform our understanding about the routes to using the Web to obtain medicine.

## **5.5. Differentiating legitimate and illegitimate online medicine purchasing**

This thesis has highlighted that distinguishing between legitimate and illegitimate online medicine purchasing is difficult. Figure 1 in chapter Two showed online medicine purchasing as a continuum from being completely legal through to illegal. It is the middle section of this continuum where the distinction between legitimate and illegitimate is most ambiguous. As already noted, the lack of global standardised medicine regulations is problematic and some academics suggest that due to confusion over jurisdiction and legislation, consumers are unaware of the illegality of their online medicine transactions (Lavorgna, 2015; Seeberg-Elverfeldt, 2009). There have been calls for the legal sale of medicine online to be easily identifiable (Seeberg-Elverfeldt, 2009); however this would involve the authorities endorsing the Web for medicine purchases more so than is already being done (i.e. via the RPSGB). On the one hand this could lessen ambiguity over whether a site is trading legitimately, but on the other it could further challenge the authority of healthcare experts by signifying that they are not needed to obtain medicine.

In examining people's accounts about the purchasing of medicine online I discovered that people understood the legal connotations involved. My data suggest that some people are aware that online medicine purchasing can be illegal in some circumstances.

Interviewees distinguished between purchases that were illegitimate and legitimate. In accordance with Martin (2014), Beth and Ben suggested that the Web was useful in obtaining illicit substances:

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*I kind of think that if I was to purchase a medicine online, that it would actually be something that I shouldn't actually have. For example, ADHD medication sounds like it has useful effects in those that don't have ADHD. So if I decided that I wanted to try it, then I suspect my only chances of getting it would be online [Beth IM2]*

*My exposure to meds is general, I have no chronic or life-threatening need. If my need was different I might be digging deeper. I've heard about the dark web – underworld of trade, it is dangerous. If I was in a position and my doctor wouldn't prescribe me something, with my level of Internet knowledge I can imagine it would be easy to access and obtain medicines [Ben T9]*

Ben highlighted that he had sufficient Web understanding to source illegal medicine. This is similar to the forum members, who were keen to demonstrate their expertise and knowledge of the Web, which will be addressed later in the chapter.

Rosie mentioned, in her interview, the way she concealed the fact that she bought medicine from the Web because it was not a “legitimate” behaviour:

*I do feel that I need to hide it, that it is something that people would look down at me for doing, that it does feel very iffy. I do feel that it is not a very legitimate thing to do; with like the fact that I'm hiding that I take drugs altogether [Rosie F22].*

She went on to describe how her family and friends were unaware that she used the Web to buy prescription medicine:

*It never really comes up in subject and I know that they definitely understand the risks about it and everyone has heard the horror stories about horrible things happening to people because they bought it online and so yeah, generally try and just keep it to myself really. It's not one of those things that turns up in conversations. I do know a few friends who are on different types of medication so they might have done it or taken it or not but I have no idea [Rosie F22].*

Rosie also noted the role that the media have in reporting “horror stories” and portraying purchasing medicine online as a negative thing to do.

Although Anthony had not told his family, he had told his friends about his use of the Web to procure illicit substances:

*At first they didn't really believe me. Even I had trouble thinking the Silk Road was real when I first got on the site. Some of them think that there's too much risk, another one said to me that this was really strange for his as he is from "the country". Another one told me that he would but he can't as he lives with his parents and he wouldn't really know how to explain to his parents receiving a shady package from the mail [Anthony IM6].*

Both Rosie and Anthony referred to risks when purchasing medicine online. This is consistent with the findings, which evidenced how risks are considered but overlooked when it comes to online medicine purchasing, which I will discuss the next chapter.

Having explored the routes to online medicine purchasing and identified that the Web, in providing the information about the availability of medicines to buy online, is in itself a primary pathway, along with how people acknowledge the legality related to purchasing medicine online, the chapter now turns to the findings on the types of medicines and the types of websites.

## **5.6. Types of Medicine**

The forum and survey data indicate that there is a wide range of substances available to buy online and that the types of medicine purchased online are far broader than suggested in the current literature.

The types of medicines discussed in the forums were greatly influenced by the selection of the forums themselves and correspond with the earlier descriptions of the forums. There were 151 instances of medicines mentioned in the conversations on the forums, involving 15 different types. Forum members indicated that prescription, unlicensed, over-the-counter and alternative medicines, as well as illegal drugs, were purchased online. However, types of prescription medicine were by far the most popular with 93% of all the medicines discussed in the forums falling into this category. Within this group, prescription-only lifestyle medicines were the most commonly sought (60%),

## *Purchasing Medicine Online: New Opportunities*

including medicines for slimming (48%), specifically Sibutramine (marketed under the name Reductil), which was withdrawn from the UK and Europe in October 2012,<sup>66</sup> and Orlistat, which is a prescription-only medicine. These slimming medicines were the most commonly mentioned medicines in the discussions, featuring predominantly within forums four and five. Other lifestyle medicines commonly discussed were those for erectile dysfunction (12%), such as (prescription-only) Viagra and Kamagra, primarily on forum one. Many of the posts featuring these medicines contained links to the websites that sold them. Non-prescription bodybuilding supplements were also discussed within this community. Antidepressants/benzodiazepines/antipsychotics, antibiotics and painkillers, and many of the brands to which discussants on forums three and four referred typically required prescriptions. However, there were also conversations about medicines that can be bought without prescription, such as menopause treatments and eczema creams, along with herbal/homeopathic and non-prescription medicines. There were also references to illegal drugs, namely Mephredone, which was previously marketed as a 'legal high' (a synthetic stimulant drug of the amphetamine and cathinone classes that was made illegal in any country within the EU in 2010<sup>67</sup>).

The medicines are summarised in Figure 10; the frequencies of mentions are in brackets. Instead of providing the brand or generic names of medicines, I have grouped them into the terms under which they are commonly known, or the recognised conditions they are used to treat.

In the survey, respondents were also asked what medicines they had bought online. There were 125 instances of medicines mentioned in the responses and these included many of the same types highlighted in the forum discussions. However, there were many more types, with 26 referred to in the survey as opposed to the 15 in the forum discussions. Even though there are differences with the overall numbers of the datasets some comparative observations can be made. In the survey prescription medicines, again, were the most commonly discussed types of medicines with 66% of the overall

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<sup>66</sup>[http://www.ema.europa.eu/ema/index.jsp?curl=pages/news\\_and\\_events/news/2010/01/news\\_detail\\_000985.jsp](http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2010/01/news_detail_000985.jsp)

<sup>67</sup><http://www.emcdda.europa.eu/publications/drugnet/online/2011/73/article2>

responses, though this is a far smaller proportion when compared with the 93% in the forums. Within the category of prescription medicines, lifestyle treatments encompassed only 20% of the responses, which is a stark contrast with the discussions in the forums. Slimming treatments were not as popular with the survey respondents (7%) compared with the forum members (48%), though the influence of the forums themselves, being dedicated to discussing certain lifestyle issues, should not be overlooked. Survey respondents also talked about OTC medicines more than the forum members did (21% as opposed to 5% in the forums). Of all the instances of medicines, survey respondents stated those they purchased most often were antidepressants/benzodiazepines/antipsychotics (18%), which require a prescription. Prescription painkillers also featured prominently (12%), and many of these were prescription medicines at the time the survey was undertaken, although the classifications of some, namely tramadol and zopiclone, have since been changed to Class C drugs.<sup>68</sup> NPS also featured more significantly in the survey responses (9%) than in the forum discussions (1%), as did illegal drugs (4% in the survey as opposed to 1% in the forum discussions).

These findings correspond with the most extensively used drugs determined by the Global Drugs Survey. It is interesting that similar types of medicines, and even illicit substances were talked about in both the forums, however the differences in greater numbers in the survey might be explained via perceptions of privacy. The survey offered more confidentiality than open forums. Yet although the forums were publicly accessible, members did discuss online medicines and online medicine purchasing. As I have previously highlighted in Chapter 4, this has ethical connotations for researchers, who need to consider if web users are aware of the public nature of their online actions on different platforms. The inconsistencies in the survey data also suggest that despite the anonymity offered via questionnaire methods, respondents may be selective with their answers, whilst online spaces such as forums, can generate naturalistic data offering greater insight into typical attitudes and behaviour. However, this information requires further investigation as claims about the data cannot be verified from the data itself. The use of mixed methods allows researchers to compare and contrast

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<sup>68</sup> <http://www.mhra.gov.uk/Howweregulate/Medicines/Medicinesregulatorynews/CON421308>

different online methods. In the interviews purchasers spoke primarily about buying painkillers. Whilst some OTC medicines were referred to, medicines that ordinarily require prescription and/or advice and interaction with a healthcare professional were talked about in detail. These included asthma medicine, emergency contraception, vitamin B12 injections, antidepressants, and antibiotics. In addition unlicensed products such as slimming pills and research chemicals emulating illegal drugs, were also mentioned in some cases. As the majority of interviewees were recruited from the survey, most of these types of medicine are duplicated from the survey findings. However, in the four interviews in which participants were not recruited from the survey, all of the medicines purchased were classified as prescription only. These were painkillers, antidepressants and antibiotics.

The results from the forum, survey and interview data support the existing literature that suggested there has been an increase in the online sales of opioid analgesics and psychotropic substances such as stimulants, antidepressants and benzodiazepines (Forman, et al., 2006a; Raine et al., 2009). The sample of the survey and interview data primarily concerned UK residents. The use of antidepressants in particular, has risen in developed countries, though it is not the claim of this thesis that it is representative. Nevertheless, this trend can be explored further. In a 2015 report (OECD, 2015) calculating which developed countries consume the most antidepressants, the UK came fourth. This was based on a defined daily dose, per 1,000 people per day in 2013. This information provides insight into the prescription habits of doctors. It suggests that doctors are (overly?) willing to prescribe antidepressants. This raises questions about why people feel the need to turn to the Web to procure them. I will explore this 'need' later on in the thesis. The report did not consider US data, however, another study<sup>69</sup> has indicated that 10% of Americans are prescribed antidepressants, which would put them as second when compared with the data on the OECD report (behind Iceland). Although, the same questions could be raised about why US citizens would then use the Web to purchase antidepressants instead, the different healthcare contexts between the US and the UK should be acknowledged.

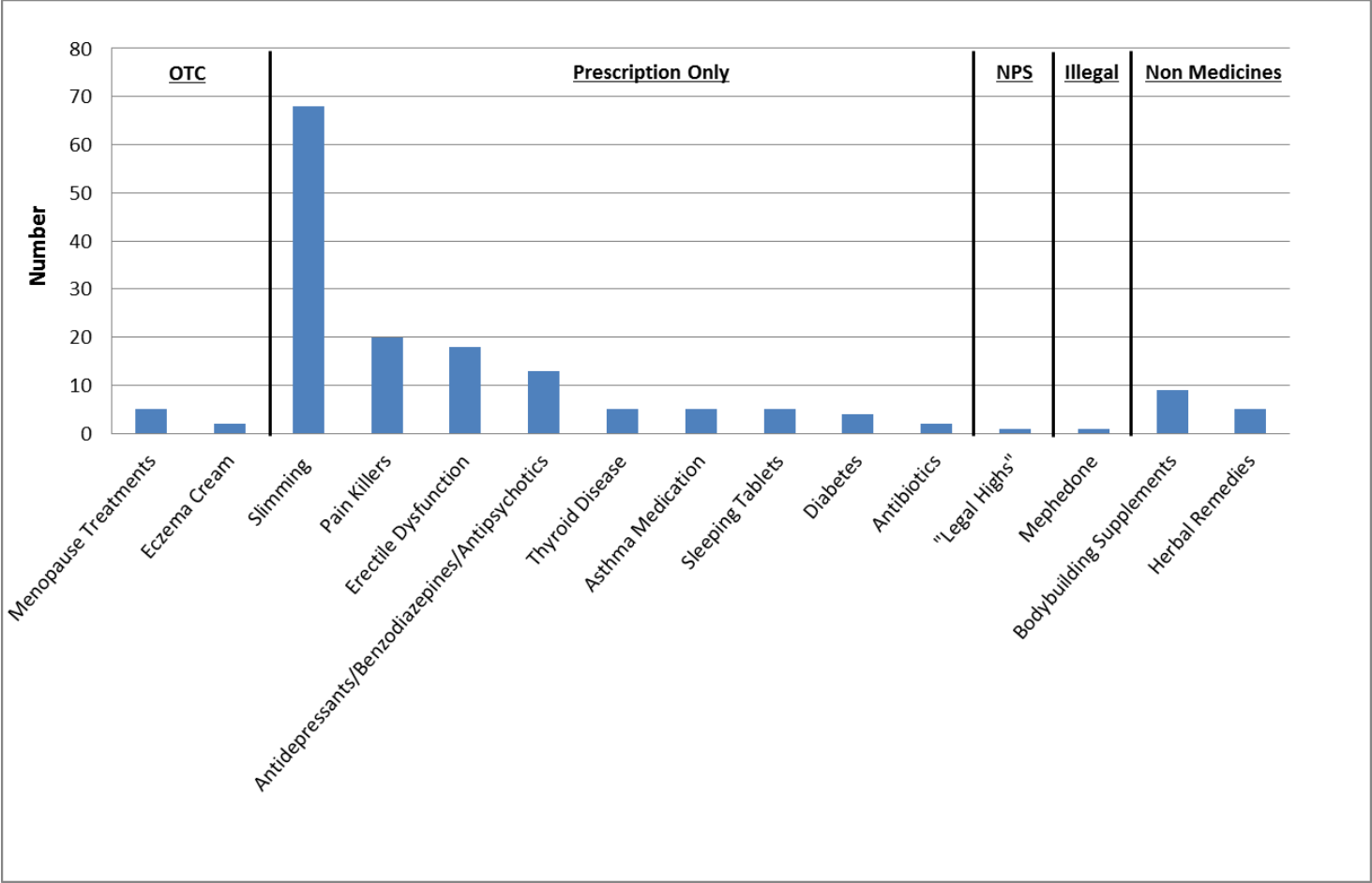
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<sup>69</sup> <http://www.theguardian.com/society/2013/nov/20/antidepressant-use-rise-world-oecd>



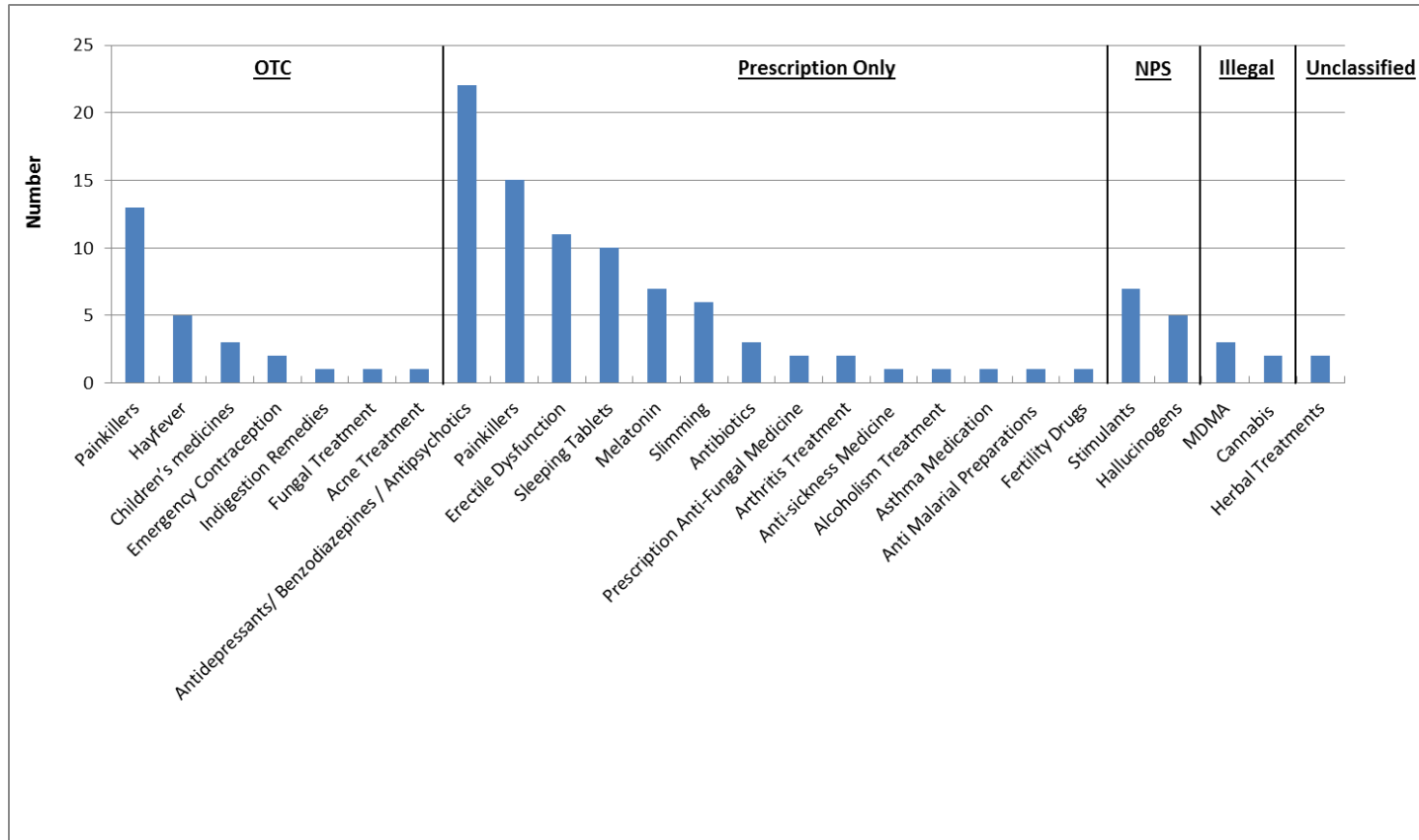


Figure 10 Instances of medicines/ conditions discussed in the forums



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Figure 11 Instances of types of medicines bought by the survey respondents





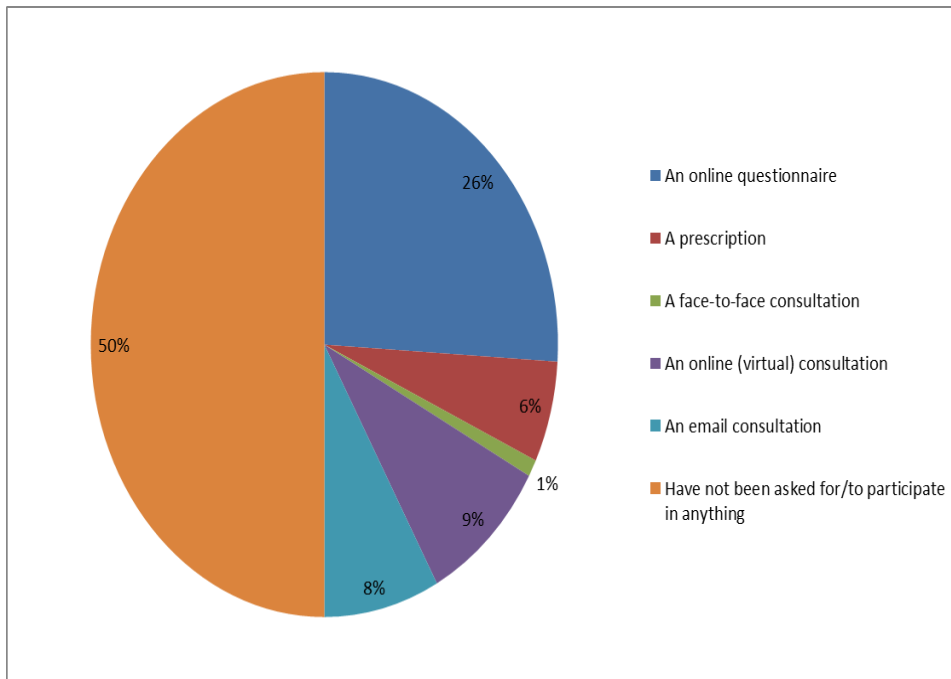
The forum and survey data show that a wide variety of medicines are available online and websites are selling them regardless of their regulatory status.

Having explored the wide range of medicines that can be bought from the Web I will now discuss the types of websites that people use.

## **5.7. Types of Websites**

Bostwick and Lineberry (2007) distinguish 'legitimate' providers of online medicine, which are comparable to authorised offline pharmacies where prescriptions are received from doctors, from pharmacies that use online questionnaires, which may be reviewed by doctors in place of prescriptions, and outlets that dispense medicine without requiring prescription. Using this typology, purchasers were asked whether they had ever needed a prescription, used an online questionnaire, had to undergo a face-to-face or email consultation, or were not asked for/ to participate in anything in order to obtain medicines. These data give some indication of the processes used, although not all the purchases discussed necessarily require a prescription. However, the data on the types of medicine purchased by the survey respondents previously discussed showed that prescription medicine was the most popular. Linking the information across the dataset I was able to conclude that the majority of purchases for controlled medicines such as antidepressants/ antipsychotics, painkillers and lifestyle substances including slimming pills and erectile dysfunction treatment, featured significantly within the category where people were not required to provide or take part in anything to procure their medicine.

Figure 12 Online Pharmacy Requirements



Only half of the respondents experienced formal checks before purchasing. This highlights previous studies, where no formal checks were made before the medicine was sold online (Gernburd and Jadad, 2007; Memmel et al., 2006; Schifano et al., 2006a). The most common requirement was the online questionnaire (26%), which has been associated with ‘rogue’ pharmacies (Bostwick and Lineberry, 2007) as there is no guarantee that a qualified doctor is reviewing the questionnaire. In addition patients can exploit the anonymity of the process and provide tailored answers to obtain the medicine of their choice. This suggests that the Web is allowing illegitimate purchasing to occur on a large scale, as the authorities fear.

In the interviews participants also noted that they were able to buy prescription medicine without having a consultation with a healthcare professional first or having a prescription. Rosie talked about how online vendors do not conduct proper checks:

*They asked have you taken it before and what doses have you taken before, and I'm not sure if they actually used checks for that, or whether it's a formality thing [Rosie F22]*

This example highlights the deficiency of the online questionnaire as a viable alternative to a proper consultation with a healthcare professional, as unscrupulous sellers can easily manipulate it. In questioning whether this was a 'formality thing,' Rosie indicated that she knew it could be a facade, just to keep up the appearance of a legitimate pharmacy. Also the questions that were asked of her did not relate to whether the medicine was suitable for her, rather it appears that the site wanted her to clarify the medicine and the dosage.

Esther also spoke about having to confirm her age via a pop up box (that she was over 16) before being able to buy OTC medicine, and having to complete an online questionnaire in order to purchase prescription medicine online

*I think there were some questions re: my general health (blood pressure, previous adverse reactions to any meds, am I using any other meds etc.) [Esther E5]*

These questions are more appropriate than those Rosie encountered, and the process appears to be more authentic. The medicine was 'virtually prescribed' by a doctor, who provided a prescription, which was then passed on to a pharmacist, who dispensed the medicine to Esther. This suggests that this website was an example of Bostwick and Lineberry's third type of pharmacy, although this is still considered a 'rogue' pharmacy by some.

The data shows the wide variety of medicines available to buy online and indicates that there are websites that do not follow regulatory standards in requiring prescriptions and consultations for prescription-only medicine.

## **5.8. Summary**

This chapter has explored web users' views about online medicine purchasing, and contextualised purchasing medicine online. The survey data provide novel information about the characteristics of online medicine purchasers and non-

## *Purchasing Medicine Online: New Opportunities*

purchasers, and some beliefs and behaviours. There are no significant differences in gender or age between those who purchase medicine online and those who do not in the particular sample in this study.

The chapter has demonstrated how the Web is changing how people obtain medicine: the Web is one of the main places that people find out about purchasing medicine online, and provides a route for purchasing. It seems that people are not accessing websites accredited by professional healthcare, but rely on information from online peers. The forum data highlight how peer influence is a factor in online medicine purchasing as per the literature. Forum members make enquiries and provide information about medicine and where to obtain it. Within the community of networked spaces, people acquire the knowledge to make purchases of medicine online. However, the survey data indicates that many online consumers continue to use traditional offline sources for medicine purchasing. This suggests that not all online medicine purchasing can be construed as challenging the marketplace, governance and expertise.

The survey data highlighted some interesting contradictions relating to whether respondents admitted having purchased medicine online. Some respondents, who had ticked the box stating that they had never bought medicine from the Web, later chose 'the Web' as a place that they ordinarily obtain their medicine from. This could be a response to the risk discourse surrounding online medicine purchasing. Utilising the interview data, further investigations into these contradictions will be undertaken, and the concept of respectable deviance will be applied to understand this presentation of self in online medicine purchasing.

My data show that both purchasers and non-purchasers are able to distinguish between legitimate and illegitimate online medicine purchasing. They understand that there are different routes to obtaining medicine that are not necessarily authorised and are aware of the risks. Illegitimately purchasing medicine online is acknowledged as an action that can evoke negative reactions. This appears to be impacting on how some purchasers are constructing their actions.

The Web appears to be used for infrequent purchases of medicine, although the survey data did not address the quantity when purchasing, and so



consumers could be making infrequent but large orders. The data has shown that people talk about the purchasing of medicine online in relation to other consumerist behaviour on and offline; they view it as part of 'normal' shopping activities. For those who buy online, both quantities and frequencies of medicine purchases increase as they become further accustomed with everyday online consumption. Some of the accounts provided in the interviews suggest that people are aware that websites may not be following correct procedures in administering medicines such that some people are aware that online medicine purchasing may be illegitimate or illegal.

The data shows the wide variety of medicines available to buy online, whilst the literature focuses on lifestyle medicines and medicines commonly associated with addiction and abuse, my data demonstrate that there is a wider range of medicine available online. Substances available for sale extend to research chemicals and unlicensed medicines. These data also indicate that there are websites that do not follow regulatory standards in requiring prescriptions and consultations for prescription-only medicine.

In the next chapter the way people are challenging conventional healthcare and expertise will be addressed, by exploring how people talk about the online purchasing of medicine. This can help us to understand more about what is driving online medicine purchasing, and how online medicine consumers view their conduct, in light of their behaviour being constructed as 'risky'.



## **6. Accounts of Online Medicine Purchasing: Challenging the risks**

*We are becoming much more empowered and more knowledgeable as consumers in general. Doctors have a place. They have training and experience. But you don't always need an expert. [F4 member d]*

This chapter looks at how individuals interpret and make sense of purchasing medicine online. Firstly it will present some shifting narratives that occurred within the interviews. In the previous chapter I highlighted inconsistencies within the survey data suggesting that some respondents may not admit their online medicine purchasing. Supporting these findings, the interviews uncovered changing narratives, whereby participants provided contradictory claims about using the Web to purchase medicine. Despite these contradictions in the data, there are some discernible themes that address what drives online medicine purchasing and how online medicine consumers view their behaviour.

Using the forum, survey and interview data, the reasons provided for online medicine purchasing are considered. The accessibility and convenience of the Web feature as incentives across the data sets, whilst need is a prevalent theme within the interviews. The chapter then considers attitudes towards legal and illegal online medicine purchasing to investigate whether people observe these distinctions. This provides the foundation to understanding how risk, deviancy, and criminality affect purchaser's views and the way they respond to the construction of their actions.

The chapter then looks at the data on risk and how people consider the 'risks' associated with online medicine purchasing, and how they frame purchasing constructed as 'risky' by external agents. The themes that emerged are entwined with some of the associated challenges and risks that were discussed earlier in the thesis, in particular expertise.

## **6.1. Changing Narratives**

The previous chapter identified some discrepancies in the survey data, regarding whether respondents had been candid about purchasing medicine online.

The majority of the interviewees were recruited from the online survey, and so I already had the information about their online purchasing. The interviews revealed some inconsistencies with the answers to the survey. Three interviewees who had clicked the box on the survey claiming that they had never bought medicine from the Web disclosed that they had during the interviews. These three interviews were conducted using different interview methods – IM, Email and Skype - and so the format of interview does not appear to be an influential factor in disclosure. Two interviewees declared that they had bought products that do not require prescription, whilst the third justified his buying unregulated psychoactive substances by questioning the interpretation of the term ‘medicine’. I will examine the three narratives in turn.

Near the end of the interview, Beth realised that although she had not bought medicine, she had bought contact lenses online, she expressed trust in offline outlets and was keen to emphasise that she used legitimate websites.

*Hmm I do actually purchase contact lenses online, which come to think of it, are prescription. However, because I use a legitimate website, I don't have any concerns. I don't think I would consider unknown websites, even if they were cheaper [Beth IM2]*

Linda had also bought various medicinal products online, even though she did not admit this in the survey. She referenced purchasing, OTC and lifestyle medicines and suggested that these were more costly in her jurisdiction.

*I have ordered multi vitamins via boots online. I was then able to pick them up at a store as I have no uk address. Also the kids vitamins are often not in stock as I tend to visit smaller and airport stores. I think I have also ordered generic aspirin like that as over here I can only get branded and they are expensive. Nothing stronger through. I am allergic*

*to paracetamol so a lot of the useful non prescription products are no good to me [Linda E16].*

Both Beth and Linda appeared not to count those purchases as medicines. Ed had also ticked the box on the survey stating that he had never bought medicine from the Web; however, he readily confessed to the opposite at the beginning of the interview. This interview was conducted via Skype, and he justified his reasons for not being honest about his behaviour from the outset.

*There are some forms of medicine that I have bought online and some forms of medicine that when I took this survey I had in mind I've not bought online. So I don't know if that clarifies it a little bit better [Ed S20].*

Ed spoke about using the Web to purchase synthetic cannabinoids, which are research chemicals that mimic the effects of cannabis. He stated that the reason he bought them was to treat his (medically diagnosed) depression and anxiety. He viewed these substances as medicinal treatments, though they are not legally available on prescription. In his opinion, they were more effective at treating his illnesses than the medicines that doctors would prescribe. The Web enabled him to obtain these substances, when ordinarily they would not have been available to him.

All three accounts indicate confusion about what constitutes medicine. However, Beth and Linda seemed to have forgotten about their purchases, whilst Ed appeared to have deliberately withheld his. These contradictions point to a design flaw in the survey, as perhaps a clearer definition would avoid such confusion. However, Ed's subsequent account suggests that some respondents may not feel comfortable disclosing such sensitive information in survey form. Ed felt comfortable enough to agree to be contacted for an interview and to be open about his behaviour in person. This suggests a difference in the way interviews are perceived by participants compared with surveys. Plummer et al. (2004) noted that a challenge for survey researchers who collect data on sensitive topics is to try to estimate just how inaccurate their data is. According to Pugh (2013), interviews can reveal emotional dimensions of social experience not evident in other methods. On the other hand, Humphreys (1970) infamous study on the *Tearoom Trade* suggested that people are more likely to endorse socially conservative positions on topics

when talking to others in social situations. The different accounts I collected suggest that I was wise to use mixed methods, and this is a theme to which I will return in the next chapters.

Ed's account presented him as pro-active in managing his own healthcare choices. He was dissatisfied with the treatment he had received from doctors and so had turned to the Web to source his own medical care. In becoming self-sufficient and free from the constraints of medical authority, he was able to challenge the expert role of healthcare professionals (Hardey, 2001). This is a theme that was also evident within the forums. For Ed, his negative experience with traditional healthcare was a factor in driving him to the Web to source the medicine he required. The chapter will now consider further incentives for online medicine purchasing.

## **6.2. What drives online medicine purchasing?**

Being a Web user and an online consumer does not necessarily mean that someone is likely to become an online medicine consumer. However, the Web can appear more convenient than traditional purchasing methods.

In the forums, the Web was talked about in terms of a more convenient place to get medicines. Some online medicines were cheaper than prescription ones, and quick delivery of medicines was also appealing.

*I just found out I can buy my prescription from an online pharmacy, which is going to be cheaper. [F2 member a]*

*I have discovered that the private cost of my drugs online is a fraction of what I am paying in prescription charges and I could get more than one month at a time => very attractive. [F3 member c]*

*I ordered them over a week ago and paid an extra £20 for speedy delivery [F5 member c]*

Convenience, cost and speed were indicated as primary motivators for purchasing medicines online in many posts; Banks et al. (2009) also noted these factors in their study of counterfeit erectile dysfunction medicine.

However, some forum members suggested that obtaining medicine at a cheaper price was not a priority, and were more concerned about the availability of specific medicines.

*The order is about twice the normal UK price but these will last me until they are available in the UK again. I just wanted to let people know that the site is legitimate but you cannot use Paypal only a credit/debit card. Thanks to previous posters for their help in pointing me in this direction. [F4 member k]*

*Found some which are a bit more expensive than normal retail price but better than not having any or buying from where they are £30.00 + [F4 member l]*

The survey respondents also highlighted cost and availability as significant influences. They were asked ‘What is most important to you when buying medicine online?’ and presented with a Likert scale from 1- 10, with 1 being the most important. The options - cost, availability, choice, confidentiality, speed of delivery, ability to bulk buy, prevention of embarrassment, reputation of the website, avoiding the doctor and the potential to purchase medicines from abroad - were chosen based on motivations presented in the literature, and the analyses of the forum discussions.

For some people, the Web might be the only place to obtain medicines. Eight respondents reported using the Web to get medicines from abroad that they could not purchase in their home jurisdiction. However, choice of medicines and avoiding the doctor were popular reasons for purchasing online. This may link to the theme of contested expertise noted in the analysis of the forums and interviews, where the doctor as a gatekeeper to certain types of medicine was viewed as unnecessary; the reputation of the websites selling medicine was important. Confidentiality and preventing embarrassment were also factors that appeared to influence purchasing, but being able to buy several items at once was viewed as the least important.

These results are shown in Figure 14. The order of being chosen first through to tenth is represented from bottom to top, with different colours for each number. The frequency of choice is shown in the corresponding block, for

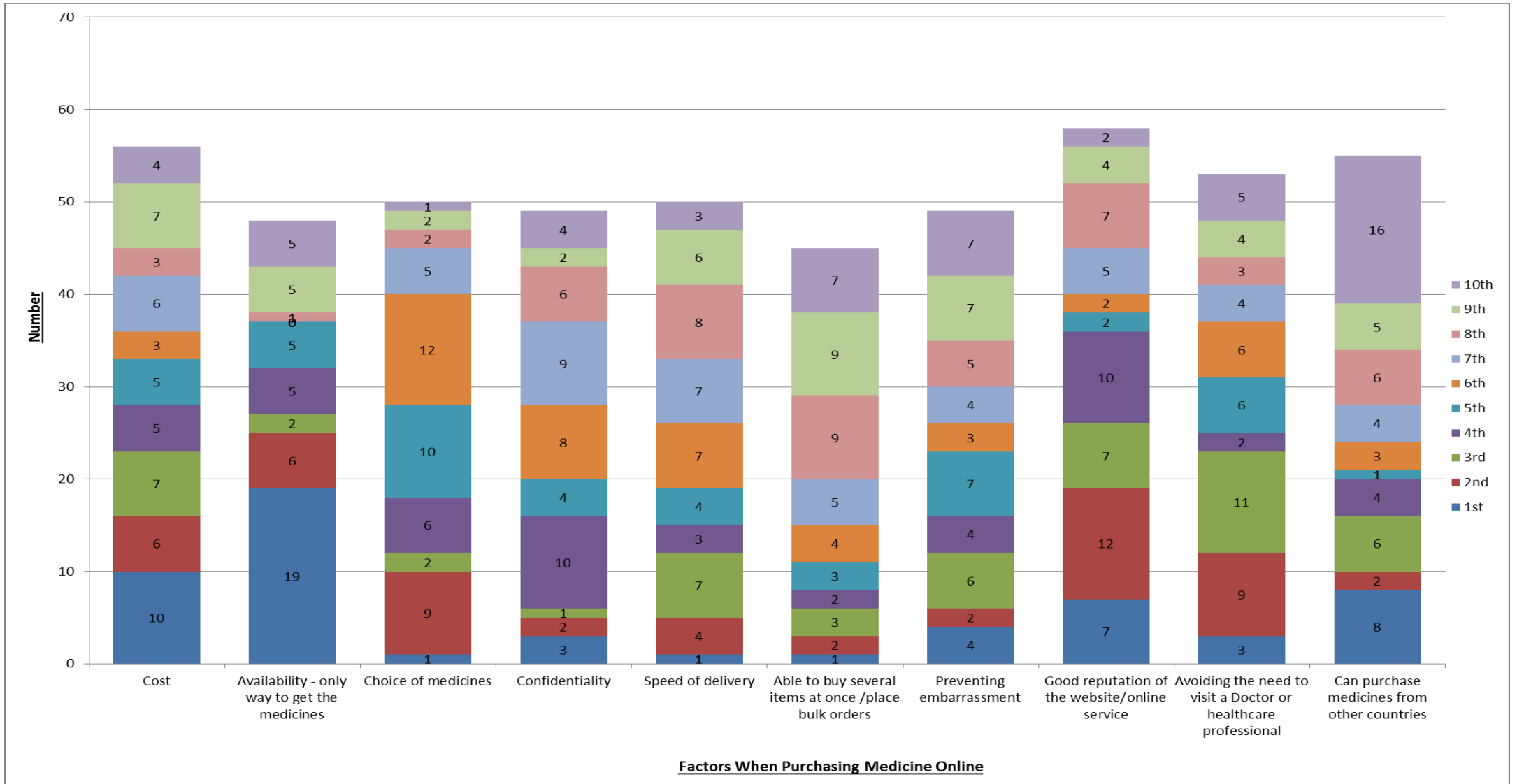
*Accounts of Online Medicine Purchasing: Challenging the risks*

example 'cost' was chosen first by ten respondents, whilst 'choice of medicines' was chosen first by one respondent.



*Accounts of Online Medicine Purchasing: Challenging the risks*

Figure 13 Factors when purchasing medicine online



### *Accounts of Online Medicine Purchasing: Challenging the risks*

In the forums the process of weighing up the various considerations of cost and availability potential often led to discussion about disincentives. Forum members frequently discussed the possible risks associated with the purchase of medicine from the Web, as the chapter will later address.

In the interviews Linda and Beth also indicated that availability and cost might prompt purchasing medicine online:

*I think I would have to go through the whole process here of tests, prescriptions and no satisfactory alleviation of symptoms before I started ordering online. But I think I would have to be fairly at the end of my tether. And there is always the question of cost. If a medicine were not on prescription but my doctor recommended it and I could order it cheaper in Germany for example, then I could be tempted. But I would probably take the medicine and show it to my doctor before taking it, just to be sure that it was not an obvious counterfeit [Linda E16].*

*Perhaps if I felt I could get it for cheaper, although again I'd only be comparing with websites I know to be real. To be honest, I don't really see why someone would want to purchase a medicine online [Beth IM2].*

Cost was also suggested as a primary motivator to online medicine purchasing by Banks et al. (2009), and was viewed as an important factor in the survey and forums.

Also in the interviews, some people said that they used the Web to access medicines that were not available to them otherwise. This is consistent with Weiss's (2006) claims that the Web allows people to bypass the safeguards of the doctor-patient relationship; Makinen et al. (2005) and Levaggi et al. (2009) have also suggested that readiness to avoid the doctor is an important factor in people choosing to buy medicine online, while the survey respondents did not cite this as a significant reason to purchase medicine from the Web, in their interviews Anthony and Kay stated they purchased medicine online in order to procure medicines that they are not authorised to obtain:

*[I use the Web] to get medicines that the current medical establishment cannot prescribe and also because it can take a very long time to get an*

*appointment with doctor here (Anywhere from a week to a year)  
[Anthony IM6]*

*I get my medicine from amazon, because it is not available at my country. Was just two times, I suffered with tachycardia and stopped using it. My main reasons were availability and price [Kay E14].*

Anthony talked about how the Web provided him with knowledge about treatments.

*It might offer better a quality of life to people that have conditions similar as I, but that aren't aware that these drugs exist, can't obtain them or don't know how to use them safely. I would have stayed oblivious to the whole psychopharmacology field and might still think that "drugs are bad" without any knowledge of what drugs are and how they can be used to help people [Anthony IM6].*

Similarly, Esther described how she had used the Web to seek information about a medicine and discovered that this medicine was available to purchase online.

*Originally, it was convenience--the first time I looked, I was looking for a physical place to buy a morning-after pill (whoops!) and I discovered you could buy several at once, online, from reputable pharmacies. Then, once I saw how easy it was to order online, I just started browsing from time to time, and occasionally I'll buy something that's cheaper or on special offer, etc. [Esther E5].*

The Web provided access to medicine for Anthony, Kay and Esther, and at the same time provided information about medicine, which encouraged these purchases. This was a notion explored by Atkinson (2009) and Eysenbach (2009) in their respective studies of how the Web has been used for health-related activities.

The Web was also talked about in terms of convenience. Isabelle spoke about how it was easier to use the Web to obtain a specific medicine.

## *Accounts of Online Medicine Purchasing: Challenging the risks*

*The normal thing that we buy on the Web is levocetirizine, it's like a hayfever medication but we buy it because it's very expensive and you normally only get, you can buy it over the counter but you normally get like seven days' worth at a very inflated price, you can ask for a generic version but sometimes they can be quite awkward to get over-the-counter so like at Boots you can ask for it and you might get it and you might not, um but you can buy it at like a fifth of the price online [Isabelle S12].*

Isabelle spoke in the interview about how she is housebound through illness, and so being able to buy medicine online was especially convenient as well as cost-effective for her. The positive aspects of being able to purchase medicine online, for example by providing greater access to medicine for the housebound or disabled and those living in remote areas, has been explored by Henney (2000), Bruckel and Capozzoli (2003) and Fung et al. (2004).

However, Beth stated that it would be inconvenient to use the Web to obtain medicine:

*For prescription medicines it is far quicker to go to the pharmacy opposite my GP practice than to browse online, and wait for it to be delivered. Also, for prescriptions, they are free here, so it would be silly for me to shop online for them when I can get them for free in the pharmacy. With regard to non-prescription medicines, I don't use them that regularly. I only really use them when needed e.g. painkillers, decongestants etc, and so as I said previously, if I was to shop online for them, whatever problem I had would probably be gone by the time they arrived. Also, I'd imagine that online there would be a minimum spend required for free delivery so the cost of delivery would probably be just as much as the medicine [Beth IM2]*

Alongside these arguments about purchasing online being convenient, some of the interviewees also talked about 'need'.

Some interviewees who had not purchased medicine online framed their decisions in terms of need; they said that it had not been necessary to turn to the Web because they were able to obtain the medicines they needed offline.

*No need to, it is that simple. It would be different if I developed the need and the doctor can't satisfy that need, for example with a chronic condition, but there would be a level of nervousness. I would go to trusted companies like Boots, Tesco rather than a chain from foreign country. There would need to be a level of desperation in me to consider that. I imagine that citizens who have long term/chronic illness and who experiencing painful, threatening conditions might need to. Also if medicines weren't as freely available from the doctor [Ben T9].*

*If the need was great enough. How great would the need be? Ummm... probably if I was to suffer physically or mentally without the drug I would get it online w/o a script. It would take a lot for me personally to do that though. Don't need to [buy from the Web]. I can access all I need via a pharmacy or the GP. I would only consider using online pharmacies if I couldn't get a drug I needed from those two sources. But for me that is a distant possibility [Harvey IM26].*

*I don't need to pay if I go to the GP so if I can get what I need there it wouldn't make sense not to. The only scenario I can think of is if for some reason I needed a medicine my GP thought would help but was unavailable on the NHS. I might try to get it over the internet then [Carole E3].*

Beth also pointed out that for her, purchasing OTC medicine offline was relatively simple:

*The thing with non-prescription medicines is that they can easily be bought in store by shopping around multiple pharmacies so people don't necessarily need to use the Internet, although I'd imagine they might if they lived in smaller areas with less pharmacies [Beth IM2].*

She conceded that some people might not find this as easy and that the Web might be a good source of medicine.

## *Accounts of Online Medicine Purchasing: Challenging the risks*

Others who purchased medicine online also used arguments about need. Julia discussed how she needed to top up her supplies of medicine:

*Solpadeine is not a prescription drug but having got “hooked” on it some years ago I found the chemist I used wouldn’t provide it on such a regular basis. I took to obtaining it from the Web but could only get one box at a time. The Web service was fine, reasonable priced, discrete packaging. No complaints whatsoever. Luckily I packed in using it some months later. This was about three years ago [Julia E13].*

Julia’s story of needing to use the Web to obtain medicine on which she was ‘hooked’ supports Manchikanti’s (2006) and Cicero et al.’s (2008) suggestions that the Web enables the abuse of medicine, as people will use it to buy medicine to feed addiction.

Purchasers ‘needed’ to justify purchasing. Rosie talked about having no other *alternative* but to use the Web to get the medicine she needed.

*I don’t know what other choice I have because I do not want to keep on ending up in hospital for days on end and nothing be done about it so, I do think it’s wrong but personally for me I don’t see what my alternative is [Rosie F22].*

This is consistent with the findings presented in the previous chapter, where both forum members and survey respondents acknowledged that availability of medicines online was a major influence to purchasing them. This is especially significant when the medicine is not available by any other means.

These accounts have shown that there were deliberate decisions to avoid healthcare expertise. In some cases, the doctor or healthcare professional was portrayed as an unnecessary gatekeeper, while other barriers noted were jurisdiction and regulation. However, interviewees talked about the way they used the Web to overcome these, whether by arming themselves with information, accessing websites in jurisdictions that had different laws or using the dark web.

Having explored the incentives for online medicine purchasing the chapter now considers whether people consider the distinctions between legal and illegal online medicine purchasing.

### 6.3. Responses to risk

According to medical authorities and organisations such as the MHRA and WHO, the risks associated with purchasing medicine online are significant. Their publicity has helped to problematise the purchasing of online medicine as risky behaviour that requires intervention. Although the effectiveness of campaign strategies warning the public about the dangers involved in using the Web to buy medicine is unclear, data from the forums and the survey suggest that many people are aware of the potential risks. Online consumers appreciate that they do have certain vulnerabilities when shopping online, and these are expanded when they introduce medicine into the types of commodity they purchase. The forum discussions in particular show how peer advice can play a part in influencing online medicine purchasing. When thinking about purchasing medicines, several members focused on risk and attempted to warn their fellow peers:

*It's a very risky business to start getting into buying drugs online and I would strongly recommend that you reconsider it. [F3 member d]*

*There are numerous problems with buying drugs on line 1. there is no assurance that you are actually receiving the drug you think you have purchased 2. drugs are Prescription Only for very good clinical reasons buying drugs off the internet, even if they come in authentic looking packets is just as risky as buying street drugs... [F2 member c]*

Financial and health risks were mentioned.

*Are you serious? The risks of taking an unknown substance are clear. Just because it's branded as lithium it certainly does not mean that it's lithium. You could end up with serious health complications. We're taught from an early age the dangers of drugs, especially because they are made up of unknown substances. Buying "medication" from an online source is likely to carry the same risks. After all, all you're buying is a name and a photograph. There's no real jurisdiction, medical or legal, with such things. [F2 member b]*

Other forum members used discussions to promote the benefits of UK based legitimate healthcare provisions:

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*I don't think you can even begin to fathom how much of a bad idea this is. I assume you live in the UK, a country with a free healthcare system. Why run the risks of harming yourself, and go to the expense of buying drugs online, when you can visit a GP and get the drugs from a reliable source, for free. [F2 member d]*

*My advice to you is ALWAYS buy from your local pharmacy if you want to be 100% certain you are getting exactly what you were prescribed. If you have a lot of prescriptions in a year you can pay a lump sum which may work out cheaper for 12 months of prescription... You may be able to get cheaper or free prescriptions if you qualify...if not I would pay and bear the cost in the knowledge that it is going to help your symptoms get better or be managed efficiently... [F3 member e]*

*Risky to say the least. You can get them for free or for a tiny charge if you live in the UK, by the way. I live in the ROI where my medication of 5 types costs 40 a month and where my antibiotics if I need them cost 79. Some drugs are actually more expensive than this. And I would still never ever consider buying medication online. [F2 member f]*

This forum member also argued that the risks involved in going to the Web as an alternative source of medicine were too great. In other posts members questioned the quality of online medicines.

*If you want antidepressants just go to your GP, they won't have a problem prescribing them if you're depressed. Also, antidepressants take up to 4 weeks to work, they're not a magic quick fix solution. Highly doubt you can buy them off the street and when buying online you'd be waiting weeks for questionable quality drugs from China/India. [F2 member e]*

This post also highlights the common concern regarding the safety and quality of medicines manufactured in developing countries, in line with advice from regulatory authorities. Similar worries were reiterated in other posts, where forum members expressed concern about fake medicines:

*Also, how will you know you are getting the real thing and not just some powder made into a tablet - worse still, what if what they use in them is harmful? [F3 member f]*



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*You need to be aware that purchasing from online chemists may not be what they appear to be and check them out first - most of these tablets are coming from abroad and may not be being produced by UK manufacturers. [F4 member m]*

The forum data suggests that member assessments of risk inform decisions about whether to use the Web to obtain medicines. This understanding of the risks and benefits will now be further explored using the survey data.

In the survey, people who had not purchased medicine online were asked ‘Why haven't you bought medicine online?’ The aim of this question was to explore reasons for not purchasing and any concerns that people had, notably the sorts of risks discussed in the forums. Respondents were provided with multiple responses in a tick-box system that included: medicines being counterfeit, medicines being unregulated in your country, medicines having the wrong ingredients, side effects of medicines, needing a prescription, medicines being illegal, credit card fraud, identity theft and fraudulent online sellers. Eleven non-purchasers provided additional qualitative responses to elaborate. These responses highlighted concerns about the fraud and the authenticity of medicine online:

*I'd worry about the quality of a product and whether it was what it claimed at all [SNP4]*

*I do not know a reliable doctor-recommended online platform. Otherwise I would!! [SNP5]*

One respondent displayed apprehensions towards both the Web and doctors:

*I am healthy and suspicious of medicines both from the Web and from actual doctors who I don't think spend enough time listening to a patient. [SNP8]*

One respondent's reason for not purchasing was not related to risk or quality but to technological barriers:

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*No credit card 2.No land line internet connection 3.use of an android phone to access the internet is limiting [SNP11]*

The non-purchasers (NP) explained their behaviour largely in terms of risks, often framed in the same terms as government and media campaigns. Consumers who have successfully been through the process of online medicine purchasing might be better at judging the associated risks than those who have never purchased medicine from the Web. To explore this the purchasers (P) were asked about their concerns whilst purchasing medicine online. They were provided with a Likert scale which prompted them to provide their opinion on statements- such as 'I am never/seldom/sometimes/often/always concerned about issues such as counterfeiting, unregulated medicine, wrong ingredients, side effects, needing a prescription, illegality, fraudulent sellers, credit card fraud and ID theft'. To align these responses with those of the NP, the options 'sometimes', 'often' and 'always' were coded as 1 (Yes) and regression analysis was used to examine the relationships between purchasing status and various concerns.

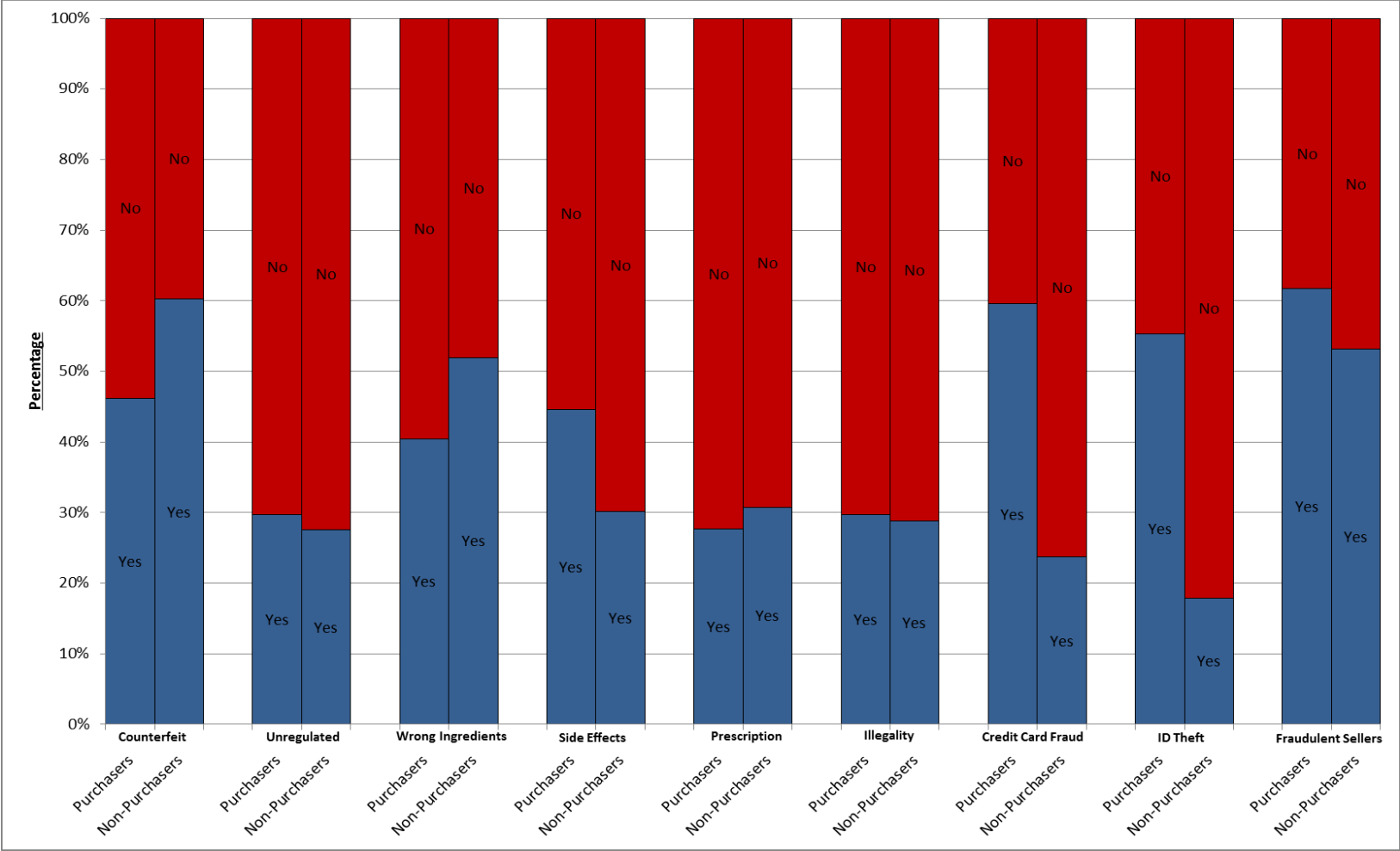
The regression analysis showed that the worries between the two groups do not differ significantly, aside from the issue of ID theft, which had a t-value of 3.268 and a significance of .001. Non-purchasers are significantly less concerned about the risk of ID theft than purchasers. These analyses suggest that NP and P share the same concerns, but for P they do not form a significant barrier to purchasing.

The data is also represented on a graph (Figure 14). As the sample sizes of the NP and the P group greatly differ, percentages were calculated in order to provide comparisons. Figure 14 shows that the two groups are closely related in their attitudes. However, there are some slight differences in relation to the financial risks, with credit card fraud and ID theft being significant predictors of concern.

The graph shows that purchasers and non-purchasers viewed counterfeit medicine similarly, although non-purchasers appeared to be slightly more concerned. There were missing responses to this question from purchasers. Unregulated medicine appeared to be less of a concern to both purchasers and

non-purchasers. Purchasers and non-purchasers appeared to share similar concerns about wrong ingredients in online medicine. Concerns about side effects of medicines appeared to be shared by purchasers and non-purchasers. Purchasers and non-purchasers shared little concern about needing a prescription to buy medicine from the Web, and similarly, both groups were unconcerned about illegal medicines. Purchasers and non-purchasers also appeared to share similar attitudes towards the possibility of fraudulent sellers online. One area where there was a difference between purchasers and non-purchasers was in attitudes toward credit card fraud. Purchasers were nearly twice as concerned about becoming a victim of credit card fraud. Purchasers were also more concerned about ID theft. Both these findings are interesting, as despite these concerns, the purchasers had gone on to purchase medicine online. These analyses suggest there is a slight but not significant suggestion that purchasers are more concerned about financial risks than health, which potentially substantiates Gurau's (2005) study, but this requires further evidencing.

Figure 14 Responses to risks



All survey respondents were given statements relating to medicine on the Web, such as: 'It is very easy to buy medicines online', 'I worry that medicines online are not genuine', 'I feel safe taking medicine bought online', 'I might be breaking the law by buying medicine online' and 'I need a prescription to buy medicine online' to rank on a scale with five possible choices from 'Strongly Agree' to 'Strongly Disagree'. These options were coded from 1-5, with "Strongly Agree" being 1, and the responses of non-disclosures, purchasers and non-purchasers were compared (Figures 15-19). As the numbers in the three groups differ, percentages were used for this comparison.

The majority of survey respondents agreed that it is very easy to buy medicine online (Figure 15). They appeared informed about the availability of medicines to purchase from the Web, even if they had not bought any. This corresponds to Fox's (2004) survey, where the majority of people acknowledged that drugs can be bought online easily, though in Fox's study the emphasis was on the illegal appropriation of drugs. This distinction in legal status is addressed in Figure 16. Survey respondents showed more differences of opinion about genuine medicines. The non-purchasers agreed that they worried about the authenticity of medicines online, as did many of the non-disclosures, but more of the purchasers took the middle ground or disagreed with this statement. Figure 17 shows a disparity in attitude between the groups. The majority of purchasers responded that they felt safe taking medicines bought online, while the non-purchasers and the non-disclosures disagreed; this may indicate that this concern is a barrier for some people. Interestingly, there is less difference in attitudes relating to legal status (Figure 18). These responses could indicate a lack of awareness of regulation or little opinion on the matter. There was agreement between the three groups that purchasing medicine online might involve breaking the law. Yet over a third of all survey respondents believed that you do not need a prescription to buy medicine online (Figure 19). However, there is a tension in trying to compare what has been reported as actual purchasing, and the hypothetical act of imagining having purchased. For those that say they have purchased medicine online, their attitudes may have been shaped by their buying medicine that cannot be legally sold, yet is not illegal to buy. Whereas in the hypothetical situations, people can imagine that they are committing an illegal act.

Figure 15 'It is very easy to buy medicine online'

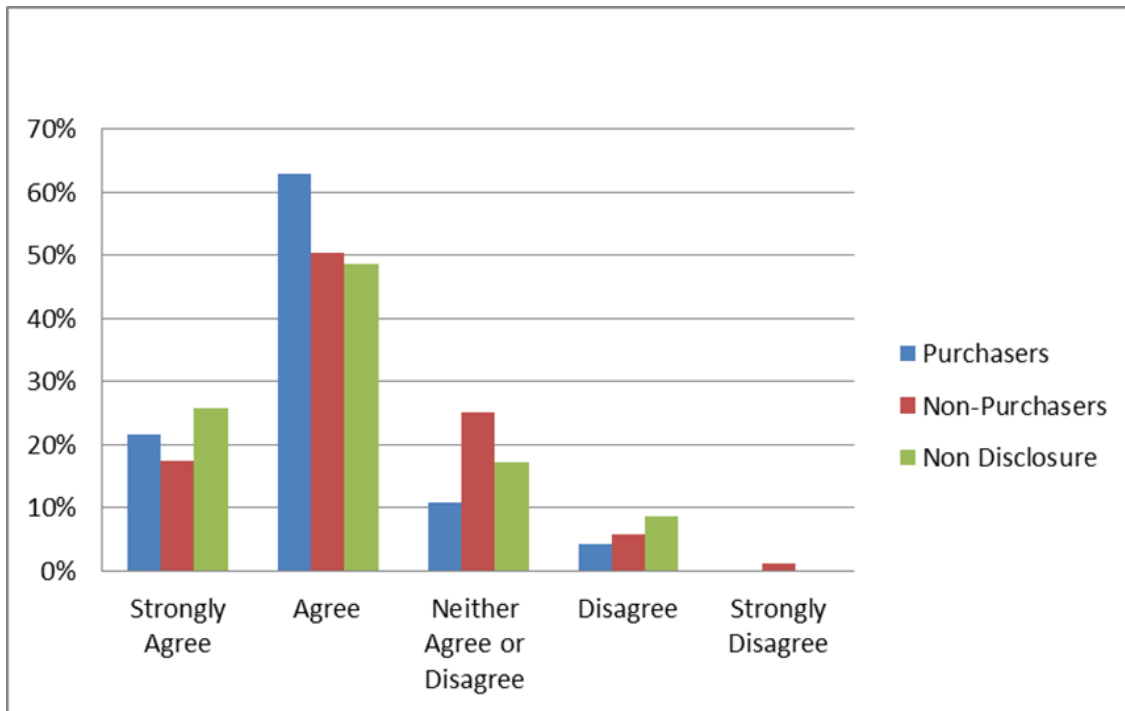


Figure 16 'I worry that medicines online are not genuine'

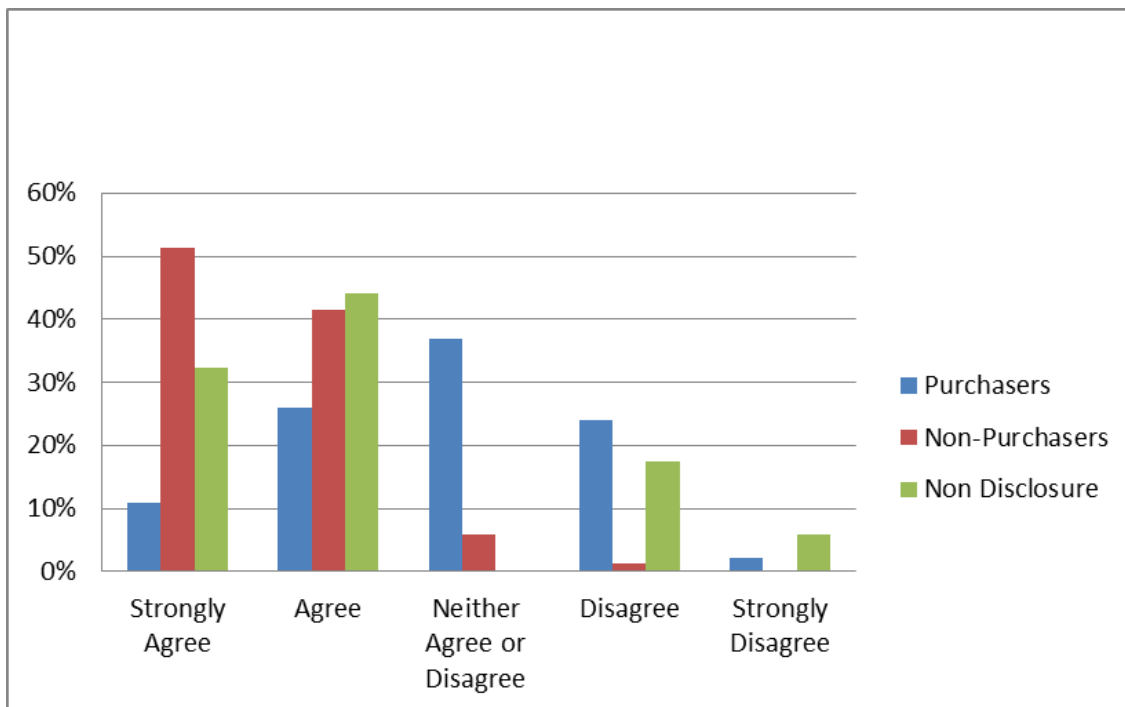


Figure 17 'I feel safe taking medicines bought online'

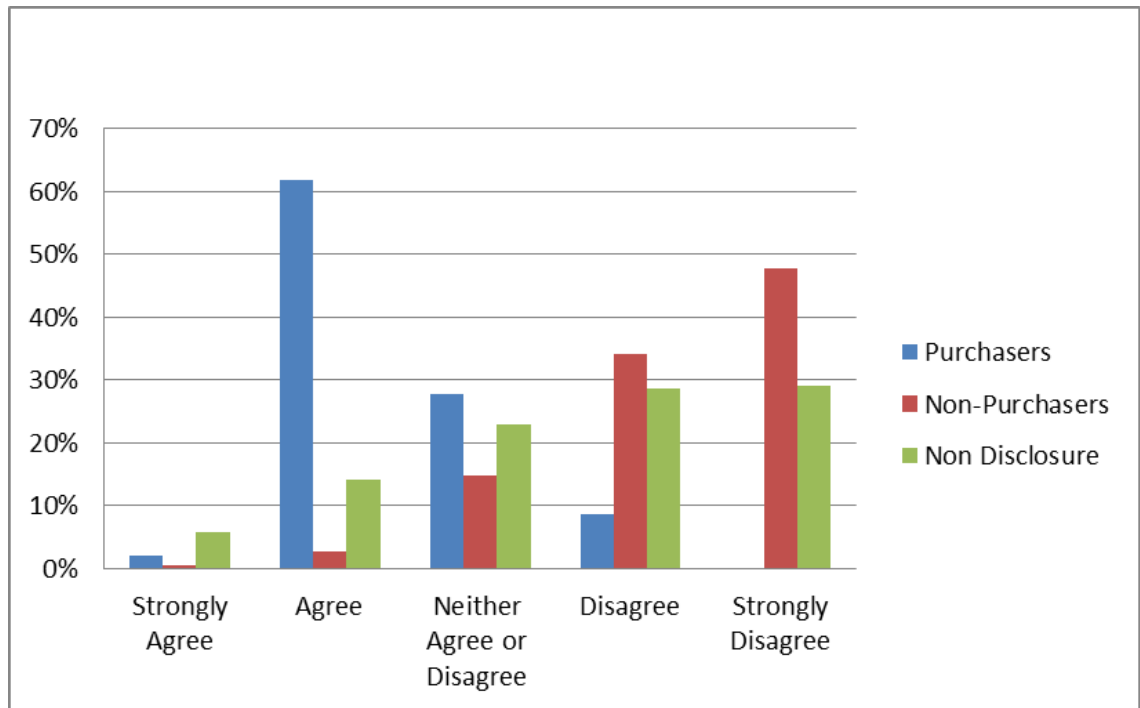


Figure 18 'I might be breaking the law by buying medicine online'

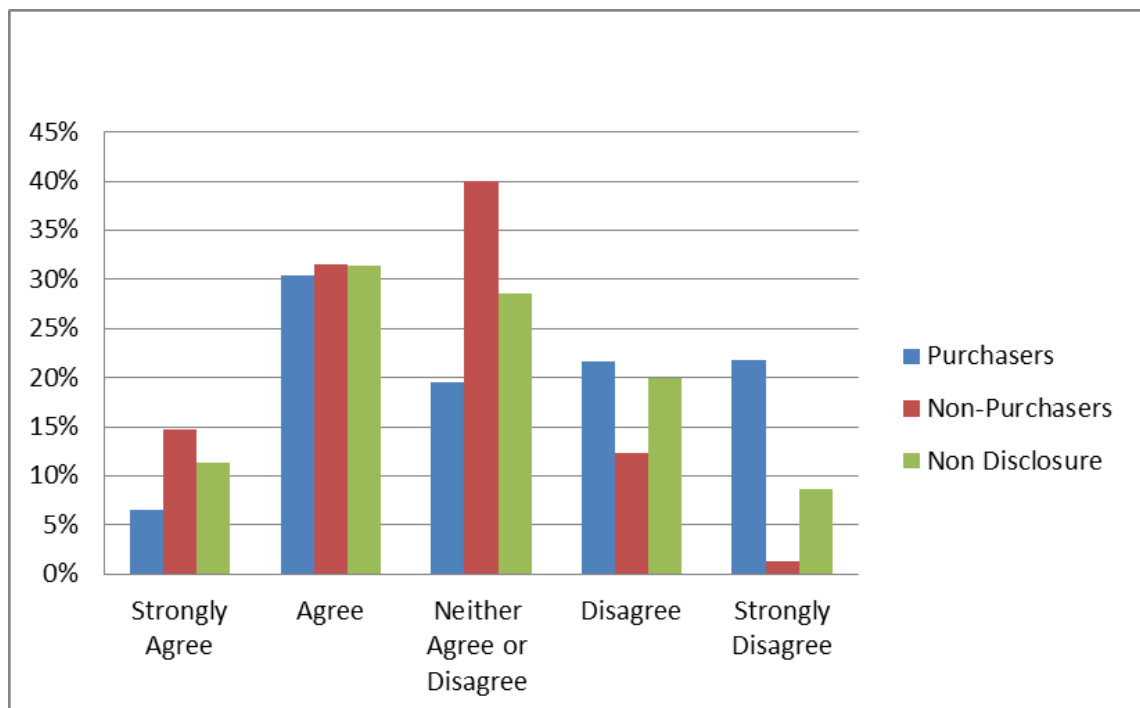
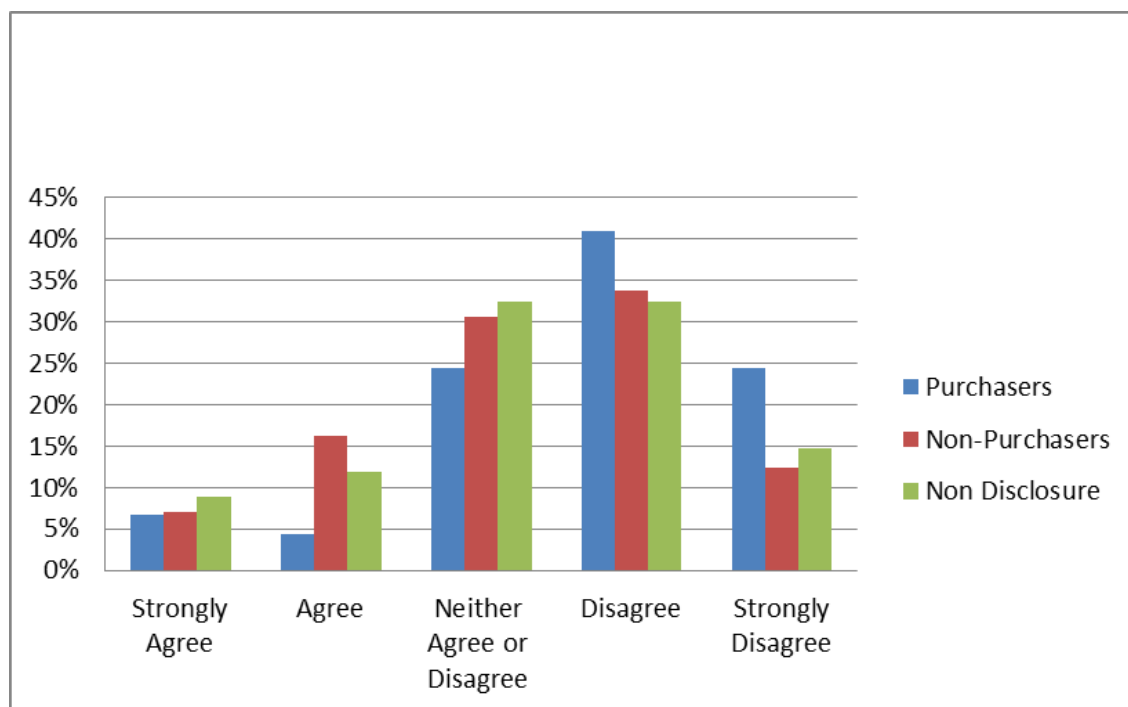


Figure 19 'I need a prescription to buy medicine online'



These analyses reveal some interesting patterns in attitudes towards the risks of online medicine purchasing. Both the forum and survey data suggest that people consider the benefits of buying medicine from the Web in balance with the potential risks associated with such purchases. However, health and security risks do not appear to discourage online medicine purchasers.

As well as concerns about legitimacy of online medicine consumption, interviewees talked more widely about safety, issues of harm and the risks of obtaining and consuming online medicine.

Rosie acknowledged that she had put herself at risk by buying medicine online. She used stigma as a reason for not disclosing her purchasing behaviour to others:

*I'd say it's probably the act of doing it. I know quite a lot of people who have been on antidepressants and with the people that I generally surround myself with there isn't really that stigma attached, but it is the act itself that, it is knowingly putting myself at risk that might make them think that I am being silly really [Rosie F22].*



Regarding the health risks, Esther talked about her concerns in relation to the safety of medicines bought online.

*It does make me a little nervous, even when using a "safe" website, e.g. a Lloyd's Pharmacy, a Boots, etc, so again, I use it for relatively minor meds. I have looked into buying prescription meds online, but I can't convince myself it's safe [Esther E5].*

Bart et al. (2005) discussed the importance of brand strength in trusting to use online websites. For Esther 'safe' online pharmacies were equated with recognisable offline brand names. Research has also highlighted how offline signifiers are influential on trust (Egger, 2001; Schneiderman, 2000; Riegelsberger et al., 2001).

Counterfeit medicines have been identified as a threat (Mackey & Liang, 2011). Isabelle explored the notion that prescription medicines sold online could be fake.

*I think in a controlled situation it's fine and you're buying stuff that is legal in the UK but I think it can potentially be quite a hazardous situation if you're not aware of what to look for, and if adverts are coming up for Viagra on the webpage, it's like oh yeah that's a great idea I'll add that to the basket without actually thinking just a minute if you can't get that without a prescription why are they selling it like that. Is it actually going to be real, I think that's just like the concern in general [Isabelle S12].*

Esther and Isabelle's concerns also align with the WHO reports on the threat of counterfeit medicines online (WHO, 2009, 2010a, 2010b). However, this has not deterred them from using the Web to buy medicine, but in accordance with Banks et al. (2009) the possibility of medicine being counterfeit has had a severely negative impact on their likelihood of purchasing without a prescription.

Finn also talked about avoiding counterfeit medicines, because he could not be sure they would contain the correct ingredients.

*My concerns regarding buying online are that the ingredients are what they are supposed to be. If I could believe counterfeit medicines were the*

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*same as licensed medicines I may be tempted to use them, as a consumer you are very unlikely to face legal action. But in reality, my concern is that I am only subjecting my body to tested drugs, therefore I will only buy what I believe are the same as what I could be prescribed or buy over the counter [Finn E21].*

The content of medicines was also a concern to David:

*I feel I could find anything I wanted, if not from a UK supplier then overseas. However, I have concerns about the purity of products available on-line. My current position is I would use the Internet to find a provider, but deal with them off-line (preferably in person) [David IM15].*

Concerns about safety and health risks were also prominent for Anthony. He talked about his concerns regarding personal liability when purchasing illegal drugs.

*Well, I'm more concerned about prosecution than the health risks, but I'm still a bit worried about the health risks. I'd be too scared to be prosecuted and frankly I think I'd rather die than have a criminal record. For the illegal drugs, I had trouble sleeping that night, but the good reviews certainly made me more comfortable with it. For the legal drugs I really wasn't worried as we don't have an analogs act here so they couldn't really prosecute me for those [Anthony IM6].*

Interestingly, Anthony described how he attempted to navigate the law, but was not completely deterred by illegal substances.

Greg and Anne highlighted their concerns about fraud, alongside worries about risks:

*I don't think they should be available online, because you don't know who you are buying from, the merchant doesn't know who you are, even though it's very easy to put in fraudulent information and to get fraudulent credit card details etc. So from both sides it's a very dodgy process [Greg F23].*

*Because I don't think there are reputable sites, it's like there's so much fake things that it's difficult to make a judgment on what is good and what isn't [Anne E1]*

However, some purchasers talked about how they dealt with their concerns. Ed described how he looked up information about substances online before purchasing them in order to guard against fraud:

*I made sure that they have a storefront, a phone number that I could call and speak with someone at a desk in a storefront. I wanted to make sure that they accept payments like a cheque: "can I send you a cheque in the mail to your store?" Like that, you know people who aren't legit, they don't have these things. They are sitting in their house right now like this; they don't have a storefront they are just trying to get your money. [Ed S20].*

Again this demonstrates how offline signifiers are used to mitigate risk (Egger, 2001; Schneiderman, 2000; Riegelsberger et al., 2001) The Web amalgamated into everyday life, rather than just used as a tool is important (Barkardjieva, 2011; Wellman & Haythornthwaite, 2002).

Rosie and Olivia also talked about how they undertook research before buying medicine online, because of the risk of fraud and monetary issues:

*I started doing a bit of background checks then because the big danger with buying online is you have no idea what they're mixing it in just to make it cheaper. That's why I generally don't go for the cheapest options. Because at least, I like the idea that if it's through a company, even if it's online then there are...you can talk to people who have used it before, there is some form of...they would have to go through legitimate means to be up and running, that's what I tell myself. If it's just some guy on the street you have absolutely no idea and I'd be very surprised if it wasn't mixed in with other things [Rosie F22].*

*Once I have decided what I want to buy I look for companies that are UK or US based, all information in English. Where possible I check for online*

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*reviews of the companies I am considering buying from and I also tend to ask friends and people whom I know have purchased similar products their opinions [Olivia E19].*

Trust in offline outlets may alleviate concerns about the risks: Nicole stated that she only purchased from online vendors with associated offline outlets, which offered her some reassurance:

*I only buy on sites that I know the companies in physical space (with a location, shop) but I know that is not enough [Nicole E18].*

Riegelsberger, Sasse & McCarthy (2005) note that offline locations can be an indicator of legitimacy, in that a 'physical' outlet is evidence of regulated and authorised products.

The data suggest that those who had bought medicine online and those who had not shared similar attitudes towards risks. They appeared uninformed about medicine legislation, and viewed online medicine purchasing as a way to bypass expertise. However, non-purchasers seem more concerned about the risks associated with counterfeit medicine. It appears that people who buy medicine online are willing to overlook the risks, and present narratives containing justifications for their purchasing. Such justifications display 'othering' techniques and contest governance, and health expertise in order to respond to or downplay risk. Those that have already purchased presented themselves as more informed and better prepared to manage the risks. It is to these findings that the chapter now turns.

### **6.4. Othering**

Frequently the data evidenced othering as a means to mitigate the risks involved with online medicine purchasing. The technique of 'othering' was used in the forums to assert moral position, suggesting that some people's behaviour needs controlling because they do not have the skills to understand information properly. Weis (1995:17) argues that othering not only "*serves to mark and name those thought to be different from oneself*" but is also a process through which people construct their own identities in reference to

others. Othering, in the context of healthcare, has also been discussed by Johnson et al. (2004), in their study of the interactions between healthcare providers and South Asian immigrant women, where social and institutional contexts created conditions for othering behaviour. Similar processes appear to be at work on the Web in relation to online medicine purchasing.

This forum post highlights the challenges facing the online patient and clearly demonstrates the problematic “others” who are at risk of self-diagnosing and rogue pharmacies online:

*You've only to read the health boards on MN to find people convinced that they have a case of “X” conveniently forgetting that the symptoms of “X” are also common to conditions “Y” and “Z”. There's already a roaring internet trade in dodgy medication marketed to the “worried well”...not to mention the vultures willing to make a fortune out of the “desperate incurables” with offers of stem-cells and the like. GPs are a mixed bunch but I would rather trust my health to someone qualified & experienced in medicine than to go the very dangerous DIY route. Second opinions are available if people aren't happy with what they get first time around. [F4 member h]*

Similar to the survey members, Fiona used othering as a way of questioning legislation. She distinguished between those who can *harm* themselves and *sensible* people (like her) who should be allowed to purchase medicine online:

*You can harm yourself any way you want to. You can drink bleach if you needed to. You know by putting rules and regulations in place it's only going to slow down people who are doing things sensibly as opposed to other ways and I think a lot of it when you look at it is well they can have it in that country why can't I have it in this one? [Fiona F7]*

Rosie also suggested that it is *vulnerable people* who are most susceptible to becoming victims. She argued that purchasing medicine online is more risky to ‘others’ who are not as informed.

*It is definitely always there in the back of my mind that I'm not entirely*

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*sure what I'm taking. For a long time I was very wary about things, like what is the sealant like, are they the same colour, the same texture as what I've had before. I was a little bit paranoid about what sorts of side effects I was going to get. But yes in the end, well what I've taken seems to have worked out fine. I would say that for me personally it's a good thing for me that I can get my medication, but at the same time I can see that it can be a bad thing, but I try to be as thorough as I can because a lot of people can't, it is very easy for a company to hide within the Web and sell useless medications to vulnerable people [Rosie F22].*

Carl also distinguished himself from less-aware people:

*I think there are some very naïve people out there, I'm afraid, who use the Web, and they aren't always aware that they can quite easily buy things which aren't legal and which aren't healthy for you. And I think it's as much their fault as it is the people who sell stuff, but I also have to remind myself that not all people, in fact most people aren't as well read up on the Web as I am and they assume because a website looks good it must be good [Carl S11].*

It is clear that the associated risks factor significantly in the accounts that people provide, and discussions about online medicine purchasing. Such risks are responded to with justifications and othering techniques.

The literature suggested that some people might be naively purchasing medicine online, as they are unaware of the risks (Liang and Mackay, 2011). However my data indicates that consumers are aware of the risks but the perceived benefits to purchasing medicine online are considered to outweigh the supposed dangers. They view themselves as distinct from vulnerable others who would not be able to manage the risks as well as them. They are different from such 'others' because they are part of a higher culture, which are less susceptible to the 'risks' (Ferrell et al, 2008). These 'informed' consumers are thus able to challenge the role of the healthcare professional.

## **6.5. Justifying online medicine purchasing by challenging governance and medical expertise**

Expertise was a theme prevalent throughout all the data. It was used to challenge institutions associated with criminal and health risks, namely the role of legislation and healthcare professionals. Although people acknowledge these structures, the Web allows them to be avoided, thus undermining authority and expertise. My data did not demonstrate challenges to the marketplace, people did not provide accounts where they criticised pharmaceutical companies and wanted to obtain their medicines elsewhere, for example. Instead the data highlighted that regulatory issues, especially concerning jurisdiction, and tensions between lay and medical expertise, are intrinsic to purchasing medicine online.

### **6.5.1 Challenges to Governance and regulation**

As well as describing doctors as a barrier to obtaining medicine, interviewees also noted how regulation affects whether or not they can access medicines. Diane talked about her frustrations that the US government has intervened in the sale and supply of medicine.

*I used to buy Meds online, and when the government banned ALL sales of mail order Carisoprodol, I became irate. It's extremely unfair and one ought to have access to a muscle relaxer, via online means, with verifiable online physician consulting.....NOBODY around here is getting the script they need and the quantity that they were formerly prescribed /require! It's a prison state where doctors are being told what, and in what quantity they can prescribe, with fear of having their licences stripped, and or prosecution as punishment! [Diane E4].*

The Web is presented as the alternative to the traditional forms of healthcare that may be expensive or inaccessible. (The Centre for American Progress Action Fund (2009) has highlighted how many people are uninsured and/ or lacking the means to access essential healthcare services and medicine.

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The accessibility of purchasing all classifications of medicines and drugs from the Web was highlighted in Anthony's interview. He spoke about accessing both the open and the dark web to buy unregulated medicines, NPS and illegal drugs. The Web provided him with the means to purchase substances that were otherwise unavailable. Although this involved engaging in some activities punishable by law, as Schneider and Sutton (1999) noted, the nature of the Web meant that these 'crimes' are difficult to detect or prosecute. Joshua further expressed his discontent with medicine laws:

*Criminalization and pre-emptive banning of substances - the fact that we put in prison people for activities that takes place between two or more consenting adults that are fully aware of the risks. Also the fact that we ban and classify substances based on no scientific evidence [Anthony IM6].*

Legislation was clearly problematic for a number of interviewees. Another interviewee, Ed, also spoke about purchasing NPS and research chemicals online. Although he acknowledged that he had engaged in something potentially untoward, he convinced himself that his actions were legitimate.

*It's a grey area here, but as far as I am concerned right now, I am within the law absolutely. I've spent a few years in jail for stealing stuff and I don't want to go back, I'm not a retard. So I made my mistake and I try to stay above the books. You have to be very careful, yeah you have to know what you have. At any time the DEA could break into my house and take anything I have and charge me with a crime and then it would get dismissed, I would get whatever they confiscated back and I would go on my happy way. I would be out about three grand in lawyers' fees and they would say sorry about that [Ed S20].*

In their responses about legislation, interviewees showed some awareness of regulatory frameworks and indicated why, and sometimes how, they navigated them. Different countries have different medicine regulation and healthcare systems, as outlined in Chapter One. Some interviewees were resentful of the limitations in access to healthcare and treatments produced as a result; for



example, as discussed above, doctors and healthcare professionals were viewed as unnecessary gatekeepers. Diane held passionate opinions about the reasons people in the US were motivated to turn to the Web to obtain medicines.

*Not everyone has a doctor all the time, and bureaucracy is trying to control our healthcare decision, down to telling doctors how much of any given medication they can prescribe to any patient, and they even check it against a computer program called "IStop" because one teenager snuck into his parents medicine cabinet and overdosed. It's truly ridiculous!...[ ]...We need access to the medicine that we, as well as a medical professional, not governed by any one bureaucracy; feel is required, not influenced by drama [Diane E4]*

Others provided similar reasons for wanting to buy medicine online. Tina talked about requiring a particular medicine that was easily available abroad but not in her country.

*In both cases I am not buying prescription drugs. However in both cases, I want to purchase items I cannot get in Luxembourg (where I live). Seems to be the only and/or best place I can buy them. The US brand Tylenol Sore Throat medicine (which I was first given by friends just back from the USA & which works brilliantly for me) is just not available over here. However, when I have tried to order it from the US Amazon site, they will not deliver to Luxembourg or UK...[ ]...I have tried repeatedly but without success to order US 'over the counter' medicine from the US, but have not been able to do so. Therefore reputable firms (or those scared of lawsuits) seem to respect the national legislation. In fact there is quite a wide range of things that you can and cannot buy sometimes across the various Amazon, ebay or other "international" sites, and where they will deliver to, that are not just determined by ease of logistics, in my experience [Tina E25].*

Marie also discussed how she turned to the Web to buy prescription medicine for a friend:

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*One of my friends from my country asked me to get some painkillers and I didn't find them here because this medicine belongs to the USA not here, so I tried to find out for him where this drug is and where can I purchase it. So I just Googled it and found a company that can deliver it to here, this medication. It requires a prescription, but because it wasn't for me I can't get a prescription for it and I know that we have, Advil is ibuprofen, we have ibuprofen here, but because he asked me for exactly Advil, that is what they wanted, so I just purchased it from the website. You need a prescription for this drug for here in the UK and I haven't got the problem that would give me this medication so because I need to give a favour to my friend, because they need it, so I bought it online [Marie F17].*

Fiona and Ian talked about how they obtained medicines online that would ordinarily require a prescription in the UK.

*I buy vitamin A, and they sell it over the counter in America, but you can only get it on prescription in this country, but you can buy it on Amazon because they import it from Thailand. I reached an age where I started to get one or two wrinkles and I thought I'm not putting up with this, so I did some research on what was the best anti-wrinkle cream and they suggested using vitamin A. A lot of these vitamins you can get from the chemists, but vitamin A, because it can burn skin and has problems with the sun has to be on prescription. I can't get a prescription for it because apparently I haven't got acne. But you can buy it online [Fiona F7].*

*While on holiday (in Malta) I had severe pain in my right knee. The normal pain killer, Panadol Extra, had no effect on the pain level whatsoever. The following morning, the Hotel Doctor prescribed Arcoxia 90mg + Coltramyl 4 mg. When back in UK I saw my own GP and related the incident, and showed him the prescription. He then informed me that Coltramyl is not a drug he could prescribe under NICE. After discussion, I suggested the internet and he agreed with me. Would I do so again if some medication was not available in the UK - for this or any*

*other symptom? Probably yes, but only after consultation with my GP and looking and assessing carefully the Internet site [Ian E27].*

Ian's account highlights the limitations that nation regulations place on the administering of certain medicines, and how the Web provides the opportunity to circumnavigate such legislation. Interestingly, Ian was careful to highlight that his purchasing was conducted with the approval of a healthcare professional, and that any future purchasing would also need to be conducted with the same medical endorsement. This notion of adhering to healthcare conventions was a theme that other interviewees such as Esther and Linda referred to when they spoke about normalising purchasing and the availability of medicines online. The accounts provided by these three interviewees demonstrate that for them, intervention from medical expertise is needed in online medicine purchasing. For some, there is a reluctance to assume complete responsibility for their healthcare management (Henwood et al, 2003).

### **6.5.2. Challenges to healthcare expertise**

In the forums there were conflicting arguments about the role of the doctor, and whether or not they were considered necessary in obtaining medicine. Some forum members directly questioned the expertise of the doctor:

*Everytime I go to the GP they either confirm I have what I think I have or say that I haven't and then when I go back a week later still with symptoms tell me I was right all along. I really cannot see the point of them beyond being a barrier between us and prescription drugs and so they can refer us to specialists if you are clever enough to look up your own symptoms and treatments and know a good source from a bad source. I feel with the help of google I could do as good a job. [F4 member a]*

The Web as an information source able to challenge the expert knowledge of the doctor is highlighted. These sentiments are echoed in another post:

*Sometimes, GPs are wrong and Dr Google is right [F4 member c]*

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However, another forum member challenged these attitudes:

*Believe me, many people have a computer and no brain at all, and arrive in the surgery with all sorts of total bollocks printed out on 30 sheets of A4 - and they really do need someone to come between them and the medication they need for the illness that they think they have! And that's just the genuine people, who in good faith believe they have some nasty illness - there are a lot of "users" out there who go to great lengths to get drugs they can take or sell. [F4 member b]*

This forum member questions the quality of lay knowledge (Eysenbach, 2002; Caruso, 1997). In referring to ‘users’ the health risks that have also been associated with online medicine purchasing, namely prescription medicine misuse, are emphasised.

Another forum member positions this debate in the context of changes in the NHS.

*You are forced to go to the GP to get permission for the medicine you need, even if you know exactly what it is. There is a really good debate to be had here. Even the NHS is pushing towards self-diagnosing and treatment through its websites. It's a fascinating question as to how “empowered” we will allow the average citizen to be. And yes, some people have researched far more about their own conditions than their GPs. [F4 member d]*

This forum member goes on to highlight the confusion arising from the ‘mixed messages’ conveyed in UK governmental campaigns that encourage the “*expert patient*” (Department of Health, 1999, 2001), which advocate that individuals manage their own illnesses and conditions, yet assume people are still reliant on healthcare practitioners to obtain the treatment. The forum member is critical of the control of the healthcare industry in this situation:

*This is what the medical industry thrives on... Insisting the public are stupid. We can handle our own banking, driving a car and parenting our children but we can't make a sensible choice about using an antibiotic cream or taking a painkiller. If you have a problem in your home, you assess the situation - maybe you need to call someone in to help. Maybe you can handle some of it yourself. Maybe you can do the whole thing.*

*It's the same! Except B&Q don't prevent you from buying the tools to do the job because you /might/ screw it up and chop your fingers off. [F4 member d]*

Obtaining medicine is presented as a process, one where the individual should be able to make their own choices and manage the risks along the way. The safeguards to protect public health are viewed as superfluous in today's 'risk society' (Giddens, 1990).

In accordance with (Giustini, 2006) other forum members pointed out that medical experts also turn to the Web to inform their knowledge:

*I don't know if I'd go as far as to call them useless ALL the time but at my last GP appointment we were both reading the internet for the best remedy for my illness - he had as little clue as I had! I wouldn't mind if it were some tropical disease, but I had hayfever!! [F4 member e]*

*My GP is extremely useless. He is honest about it though. He often says "Oh I don't know what that could be, I will just look it up on the internet." Well usually I already have. The only difference is I can't write my own prescriptions and I don't get paid a fortune. [F4 member f]*

While some expressed dismay that doctors looked up information on the Web, others appreciated that doctors may not know everything and were happy for them to research information online:

*I have no problem with a GP hooking up to Google if he/she needs to find out more about something - they are doctors and more often than not they are overworked.*

*So they don't know about the new x, y or z - maybe that's because they are overworked, knackered and haven't had time to read it. Likewise there are many different remedies for minor ailments - I would far rather my GP said "am not sure if this will be suitable" and got googling than prescribe me something I could not take. My GP is brilliant and far from a waste of space. [F4 member g]*

These forum posts confirm Hardey's (1999) view that new media technologies such as the Web can empower patients and create "a new struggle over

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*expertise in health that will transform the relationship between health professionals and their clients” (1999:820).* These forum posts highlight this struggle over expertise. As we can see here in the forum data, some patients use the Web to resist medical expertise on health and illness.

The interviewees also drew on their own expertise in order to legitimise purchasing medicine online. In doing so, they frequently adopted an anti-orthodox medical stance to support their actions. They drew on lay and experiential knowledge in order to appear authoritative and expert.

John began by stating that he thought a medical expert should diagnose people's conditions:

*The vast majority of people should not self-medicate and should work with a healthcare professional so that the right choices are made in an area that is often large and complex. A professional can help arrive at the correct diagnosis and then making a suitable first line selection of medicine that may be of benefit [John E28].*

This corresponds with Hardey (2001) who claimed that people still want to maintain elements of the traditional doctor-patient relationship. But Bernard also went on to question the paternalism of healthcare professionals:

*Though it is simply not true that only a doctor knows what medicine to prescribe, at what dosage and for what duration. There are people who can make even better choices than would be recommended by their doctors. Doctors can often not listen to patients because of arrogance and ignorance. I have known doctors to go against the evidence or make choices that are not suitable or even harmful. There needs to be the ability to make small purchases of medicines without any intervention. Though the advice should be that everyone should seek professional advice when it comes to medicines [John E28]*

Dissatisfaction with doctors encouraged others to purchase medicine from the Web. Rosie explained how she bypassed the traditional way of procuring antidepressants:

*I found that I started to trust the doctors less and less at that point. I didn't really see the point of going to them anymore and the Web seemed to be the only other alternative that I could actually go to for medications because things like antidepressants are not available in supermarkets and if you go to a street pharmacist you have to show them the prescription. So the Web was the one way that I found round that [Rosie F22]*

These individuals use the Web to acquire knowledge and experience about medicines and manage their illnesses. These accounts reveal a friction between the medical and the lay expert.

Linda criticised doctors, but was equally critical of lay expertise:

*I think that people are generally glad when they are healthy and pain-free and that medicines are not something that people want to think about unless they really have to. Doctors and hospitals also hide behind patient confidentiality to avoid having to be more transparent about medication and methods, and so the broad masses remain blissfully ignorant until some ailment hits them and then they are forced to learn fast. Or rely on the limited information that a (trusted) doctor is prepared to give them. The internet provides a huge amount of information for self-awareness, but this must also be taken with a pinch of salt (or even better: compared with the information from a qualified doctor) and I accept that not everybody has had the education and experiences that I have, so they are not equipped to do that in many cases [Linda E16].*

Fiona talked about how she shared medicines, which led her to run out of her own legitimately obtained supplies. Knowing that sharing medicines was wrong, she did not want to disclose this to her doctor, and the Web allowed her to avoid this.

*So I bought Ventolin from a private practitioner online. I ran out, I didn't go and tell my doctor that I was using quite a lot, because I was sharing it with somebody else. They were asthmatic and they couldn't get it over in this country so I gave them a couple of inhalers. I had to get some*

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*more, so I got a private prescription online and it was delivered to my house which was really easy but I also use a prescription strength anti-wrinkle cream which I have bought from somewhere like Amazon, strangely enough. So I have used pharmacies, online pharmacies, and I have used other sites which you might not think are medical [Fiona F7].*

Medical expertise was contested, and the Web was used to circumnavigate regulation. This highlights the mobilisation from patient to consumer, where individuals are proactive in managing their own healthcare choices, as in Hardey's notion of the 'patient' or 'user' as 'consumer' with the implied ability to make decisions based on information and experience (Hardey, 2001). Tensions between professional and lay medical expertise emerge from consumers drawing on their knowledge and experience obtained from being web users, which threaten traditional means of obtaining medicine and the paternalism of health care.

The interview data further evidenced the way healthcare professionals are seen as unnecessary barriers to obtaining medicine.

John stated that people should have the choice about whether or not to include a medical professional when deciding where to obtain medicine.

*I think it is important that people are able to buy medicines online with the ability to either completely bypass medical professionals or with the oversight of a medical professional should they so want it. [John E28].*

Others talked about their challenging experiences with healthcare professionals. Olivia explained that she was driven to buy medicine from the Web, as her doctor would not prescribe it to her.

*I normally obtain any medicines that I need by prescription from a Doctor. In the past, about 6 years or so ago I purchased medicines from the internet as my doctor was unwilling to prescribe these for me. I found information about B12 through my own personal research. The Doctor was unwilling to prescribe B12 because they said I had not been diagnosed with B12 deficiency [Olivia E19].*



Olivia was not able to get the medicine she says she needed using a legitimate route, and the Web, as an information resource for health (Eysenbach, 2009), provided her with knowledge about online medicine availability.

Sophie turned to the Web because she knew that a pharmacist would not have given her the medicine.

*I'm not classed as either overweight or obese by my BMI so there is no way I would have been given it by walking into Boots to ask, however, I feel that's discriminating to people that are a little overweight and just need a helping hand. I was going to the gym but I just needed a little extra motivation to lose the additional pounds and the pills worked, I lost some weight. It was a very slow process and I by no means abused the drugs (as I assume a pharmacist would of expected me to), but purchasing online was the only way to get it [Sophie E24].*

This avoidance of the pharmacist is affiliated with the theme of availability and using the Web to bypass the doctor (Makinen et al., 2005; Levaggi et al., 2009), which will be addressed later in the chapter.

Others expressed their frustration at experiences with doctors, where their personal knowledge had been called into question. Finn gave this account of how he was compelled to source treatment online:

*Suffered from Acne for over 30 years, albeit now it tends to flare up rarely. In recent years I have been prescribed topical cream containing antibiotics and oral antibiotic tablets and found these to be very effective, used for a course of short treatment and no further problems for many months. Having moved house I attended my new GP when I had a bad facial outbreak. I was advised to make sure I had a proper skin care regime, to wash thoroughly and take care of my skin; the advice being given by a doctor just out of university working for some 6-months at the surgery. Despite stating to him what had worked for me previously and that having been a sufferer for so long I did know something about trying to care for my skin he clearly felt a thorough wash with some soap was what was needed! [Finn E21].*

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Sophie also discussed potentially buying other prescription medicine online, if her doctor were to refuse to prescribe her medicine.

*I would consider purchasing my Xanax from there moving forward if they were required again just to avoid all the awkward conversations at the pharmacist (which were asked in front of a crowd of people). There is quite a stringent Q & A process with my GP that I have to go through prior to receiving a prescription. At the minute it has always been fine, however if I changed GP for instance and they refused a prescription then I would seek the medicine elsewhere...[ ]...I'm also prescribed Propranolol for nervous tremors, which I take when I present at work. If I could not get this prescribed by a doctor any longer then I would definitely purchase from the web as I have come to rely on this to perform at work [Sophie E24].*

In accordance with the literature on purchasing Viagra online (Banks, 2009; Eysenbach, 2009), Fiona talked about occasions where people are *too embarrassed* to visit a doctor:

*Everyone knows the stories and the emails for Viagra and stuff, which you know I don't obviously need Viagra - not being the right gender, but you look at it and the stuff they do sell you also see embarrassing illnesses as well, so it's stuff you wouldn't go to the doctor with because you would be too embarrassed [Sophie F7].*

Carl also noted that the Web allows people to overcome any potential humiliation.

*It's appealing to people, people getting embarrassed about things, it makes it easier for them to buy things which they may feel embarrassed to ask for at the doctor's. I don't have that problem [Carl S11].*

Confidentiality and the perception of being anonymous have been suggested as reasons why people purchase medicine online (Makinen et al., 2005; Levaggi et al., 2009). These also fit in with wider preconceptions of Web use and online behaviour, where people act under the presumption of anonymity (Wall, 2007).

The data highlights how healthcare expertise is not limited to the professional as the public can access the same knowledge and information, previously only available to doctors, nurses and pharmacists. Online medicine consumers in

seeking new routes to obtain medicine and healthcare information are using knowledge and expertise to problem solve in their everyday lives (Giddens, 1990). This creates a tension between experts and citizens as people are challenging why they need regulatory bodies to make healthcare decisions for them.

However, though the forum discussions and accounts indicate that purchasing medicine online is a reaction to authority, further analysis suggests that it is not deliberate. The act of seeking and purchasing medicine away from the doctor/regulated channels is not driven by the notion of challenging healthcare expertise, although this is an inevitable outcome of purchasing medicine online.

## **6.6. Summary**

This chapter has presented key findings from the study and explored what people said about online medicine purchasing to explore what drives the behaviour and how it is viewed.

Like the contrasting survey data, the interviews also demonstrated that some people hide their online medicine purchasing, while others presented contrasting accounts depending on the data collection method. Explanations for not being originally forthcoming about online medicine purchasing included memory recall and confusion over what constitutes medicine, rather than concern over how the activity might be judged. These changing narratives also highlight the importance of methodological pluralism in uncovering such insights.

The reasons for purchasing medicine from the Web were also explored. It appears that cost/ benefit analysis is undertaken, where incentives such as availability, ease and convenience are weighed up against the risks. There are some overlapping narratives between themes and between those that have purchased medicine online and those that have not. Availability of medicine online was a common theme, as with the survey and forum data, and interviewees spoke of it as a key influence on purchasing. This was intertwined

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with need, where people 'needed' to use the Web to obtain medicine that could not be procured via traditional means.

Risk factors were also presented as possible barriers to purchasing, however, some online medicine consumers challenged the risks of online medicine purchasing by disputing governance and medical expertise. In particular, 'othering' was used as a technique to mark consumers out as 'experts' as opposed to others more vulnerable to the 'risks'. Such justifications are puzzling when set alongside the initial accounts of online medicine purchasing as normal consumerism that were discussed in chapter five. If it is indeed 'normal' consumerism, then why do certain individuals feel the need to justify it?

The next chapter will discuss the theoretical perspective – respectable deviance that was used to inform my analyses inductively.

## **7. Respectable Deviance**

*The healthcare environment is changing. People are becoming empowered in more areas of their lives and doing things online that they would never have been able to before. [F4 member d]*

This chapter provides a theoretically informed interpretation of online medicine purchasing, specifically how and why people discuss the action in the way they do. It will demonstrate a new application of existing criminological and sociological theories, combining deviance, techniques of neutralization and presentation of self, to conceptualise respectable deviance online. The three stages of respectable deviance are explored and supplemented with the empirical data. In the first instance I will discuss the deviance involved in online medicine purchasing where it involves heightened levels of illegitimacy, before considering how people are compelled to provide justifications for online medicine purchasing and that presentation of self is carefully managed in order to maintain respectability. Respectable deviance explains how people who purchase medicine online view and manage their conduct in response to it being constructed as a risky behaviour. Techniques of neutralization is the mode of performance management relied on by online medicine consumers who are purchasing illicit or illegal medicines.

Although I reviewed relevant literature on purchasing medicine and considered criminological work about deviancy, I needed to find an analytical framework to help me make sense of these data about purchasing medicines online. That framework was provided by cultural criminological and theories about respectability, and deviance. This take on purchasing medicine online emerged and matured through the process of collecting and, especially, analysing the data.

### **7.1. Online medicine purchasing as a ‘deviant’ behaviour**

This exploration of online medicine purchasing has shown that the ‘problem’ is more than a mere construction. People can circumvent official routes and medicine regulation is bypassed but this is a loophole rather than a crime, and it is afforded

by the unique nature of the Web. Fears for public health mingle and compete with commercial concerns about profit and brand reputation. Web purchases of medicine are rarely risk-free. The main risks associated with online medicine purchasing relate to the purchaser being vulnerable to counterfeit medicines, criminal activity, and/or health risks. In the previous chapters I have explored how and why people purchase medicine online and contextualised the issue of online medicine purchasing. I have also addressed how people respond to the risks of online medicine purchasing. Regardless of whether online medicine purchasing is formally classified as a deviant act some consumers offered justifications for purchasing that echo criminological analyses of deviance.

## **7.2. Justifying ‘deviant’ online medicine purchasing**

When discussing purchasing medicine online, the individuals I spoke to and those participating in forums and surveys described it as a normal mode of consumption. Purchasing medicines online was comparable to other forms of shopping on the Web. Many of the medicine purchases they described were not illegal. The accounts of online medicine consumers who were purchasing prescription, unlicensed or controlled medicine attempted to present these actions as respectable to me and to their respective communities (whether online – forums, or offline – peers, families, friends).

Online medicine consumers used justifications about being responsible for adopting their own risks, becoming experts in healthcare knowledge and practices and ‘othering’, especially when making illegitimate purchases. In some cases even people who only purchased OTC medicine also presented similar justifications. As these kinds of accounts correspond with criminological literature on people’s management of their criminal and deviant behaviour I employed deviancy theory to try to account for the way that people navigate purchasing medicine online.

The illicit purchasing of medicine is an existing practice intensified by the Web. Therefore, it is an example of what Wall (2001) terms a ‘hybrid’ crime, it is an illicit action, which can also be conducted in a similar fashion offline, but has been

appropriated by the online world and shaped by the technological opportunities afforded there.

In accordance with Box's (1983) assertion that "who you are" is more important than "what you do", people are provided with the opportunity and convenience of purchasing medicine online simply by being a Web user. Wall (2007) has discussed how the Web has created new opportunities for criminal activity. In my study people acknowledged these novel affordances, as Esther stated:

*Once I saw how easy it was to order online, I just started browsing from time to time, and occasionally I'll buy something that's cheaper or on special offer, etc. [Esther E5].*

Elsewhere Castells (2001) has argued that the Internet society has altered relationships of power, production and consumption and thus transformed criminal behaviour. The Web has increased change and emphasised the idiosyncrasies of late modernity, specifically the 'discontinuities' highlighted by Giddens (1990) that isolate modern and traditional social orders. This is confirmed in my study, which suggests that the roles of the expert and the novice in relation to healthcare have become more fluid online. In the forums online medicine purchasing was a site of resistance to medical expertise and power:

*I really cannot see the point of them [doctors] beyond being a barrier between us and prescription drugs and so they can refer us to specialists if you are clever enough to look up your own symptoms and treatments and know a good source from a bad source. [F4 member a]*

*You are forced to go to the GP to get permission for the medicine you need, even if you know exactly what it is. There is a really good debate to be had here. We are becoming much more empowered and more knowledgeable as consumers in general. [F4 member d]*

However, this new way of obtaining medicines comes with new risks and harms, which were acknowledged throughout the study.

*It's a very risky business to start getting into buying drugs online and I would strongly recommend that you reconsider it. [F3 member d]*

*Also, how will you know you are getting the real thing and not just some powder made into a tablet - worse still, what if what they use in them is harmful? [F3 member f]*

*It is knowingly putting myself at risk that might make them think that I am being silly really [Rosie F22].*

The analysis presented in Chapters five and six suggests that many people are aware that purchasing medicine online is problematic, especially where medicine is more regulated and controlled. The forum members talked of 'banned' medicines and engaged in conversations that considered the legal implications of purchasing.

*Do you mind me asking where you order them from? Because they've just banned them in the EU and I can't get hold of any anywhere! I really need some [F4 member n]*

*can anyone advise.....I have been taking for 3 weeks now and lost 1 stone and am feeling a lot more confident and happy in myself.....however.....I went to re order the tablets online from where I purchased them before as I have ran out only to be told that they are no longer available in the Eu. I am very unhappy about this and have tried lots of uk websites to try and buy them but are having no luck [F4 member o]*

The survey and interview participants described negative outcomes associated with circumventing authorised channels to buy medicine. Some survey respondents who had purchased medicine online thought that they might be breaking the law in doing so, yet this did not deter the purchase (see Figure 19). In the interviews, Anthony and Ed expressed concern about their purchasing but felt that the Web allowed them to stay ahead of the law.

*For the legal drugs I really wasn't worried as we don't have an analogs act here so they couldn't really prosecute me for those [Anthony IM6]*

*It's a grey area here, but as far as I am concerned right now. I am within the law absolutely. I've spent a few years in jail for stealing stuff and I don't want to go back, I'm not a retard. So I made my mistake and I try to stay above the*



*books. You have to be very careful, yeah you have to know what you have [Ed S20]*

My data suggest that people manage their presentations regarding online medicine purchasing. Goffman's concept of the presentation of self provides a useful explanation for the way individuals manage their performances.

### **7.3. Managing Respectability**

The brief review of existing research applying Goffman to digital interactions in chapter three shows that his ideas continue to resonate, and this chapter looks at how they can usefully be applied to understand the specific issue of purchasing medicine online - that this chapter will now turn.

Deviant-type activities are usually confined to the "backstage", where the wider public audience has no access, so that behaviour remains socially invisible (Goffman, 1959). However, once that information becomes discernable upon the "front stage" where the self is performed, the masquerade has deteriorated and that person is capable of being rendered deviant in the eyes of others. Sherry Turkle suggested "*when we step through the screen into virtual communities, we reconstruct our identities on the other side of the looking glass. This reconstruction is our cultural work in progress*" (Turkle, 1995:177). The Web is a digital space where identities can be made and remade. Identity and social processes are intertwined with technology, and individuals are able to have shifting and multiple personas online. While distinctions between public and private online spaces are not physical, there are often boundaries (firewalls and restricted password access areas, private messages) and codes of conduct for interactions (even if these may be more regularly breached) in different virtual spaces. What is interesting about the Web is that the boundaries between private and public spaces are often blurred and permeable.

This study has suggested that some people online are careful about the way they present and perform. For example, in the forums, some members who discussed how to purchase 'banned' medicines appeared to be aware of their vulnerability;

they managed their presentation by requesting the conversation be continued in more private spaces, away from public view.

*Better news is I know where you can get them for cheaper but I can't advertise it on here so pm/email me if interested [F4 member p]*

Such forum posts highlighted how Goffman's 'front and backstage' ideas apply to behaviour online. Some forum members indicated awareness of the "criminal" connotations associated with engaging in behaviour outside of regulation.

The nature of web interactions is that individuals can manipulate or amend their presentations of self. But they may be less aware of the potential audiences for these presentations. In public spaces, individuals are expected to 'fit in' and not attract undue attention. This includes not being drawn into strangers' conversations (Goffman, 1971). However, the Web allows users to intrude upon others' communication, as posts and messages may be 'overheard' by stumbling upon them via links and web searches. The normal etiquette is not always followed, as users may interject, as in this response to a forum post about buying medicines on the Web:

*Nobody should buy drugs off the internet. It is stupid, dangerous and not reliable. The sister of a friend is DEAD because she got some sort of anti-psychotic from a website. She wasn't crazy, but googled her symptoms and decided she was [F2 member f]*

Goffman (1959) used 'copresence' to describe how people are perceived when in close proximity to others, where they may overhear and observe the conversation of others. On the Web, information may be posted for a particular audience; however, it can stay online and be accessible for many years (or even forever) and so the possibility of copresence is far greater.<sup>70</sup>

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<sup>70</sup> This is beginning to be understood in the context of the debate surrounding the EU regulation regarding 'The Right to be Forgotten' ([http://ec.europa.eu/justice/data-protection/files/factsheets/factsheet\\_data\\_protection\\_en.pdf](http://ec.europa.eu/justice/data-protection/files/factsheets/factsheet_data_protection_en.pdf)), which seeks to give people the right to request that companies remove embarrassing, inaccurate or personal data from their databases.

Goffman's concept of stigma is useful for thinking about the Web. In the interviews, participants recognised that certain medical conditions or reasons for purchasing medicine may induce stigma. The Web allows people to manage their presentation of self to reduce the negative impact of stigma by making purchases less visible. The success of a performance is threatened by cues and information that could undermine the image that is being purported. Hence, for Goffman (1968:13), stigma is "*an attribute that is deeply discrediting*" and one that is "*incongruous with our stereotype of what a given type of individual should be*". A stigma is a discrediting attribute that an individual may be proved to possess, which, if known to others, would shatter the illusion of the projected social identity. Goffman makes an important distinction between the "*discreditable*" and the "*discredited*" (1968:14). The former is an individual whose discrediting information remains concealed; who may make significant efforts to ensure the discrediting fact is not disclosed in order to protect their desired social identity. The prime dramaturgical task is one of 'managing tension'. The Web appears to offer new ways to manage 'the self' or selves and potential stigmatisation. People can conduct medicine purchasing away from regulated channels, and perceived societal norms appear to be removed or reduced online.

The data showed that people who were buying prescription medicine or unregulated substances were less open about the purchasing to others. In the studies, individuals attempted to legitimise and justify their behaviour. Some did this by making claims about need. In Rosie's case, she provided justifications for her medicine purchasing by claiming that the Web was the only way she could get the medicine, but kept this hidden from others.

*I do feel that I need to hide it, that it is something that people would look down at me for doing, that it does feel very iffy. I do feel that it is not a very legitimate thing to do; with like the fact that I'm hiding that I take drugs altogether [Rosie F22].*

In these circumstances, the stigmatising labels were avoided via a careful process of 'information management'. Goffman notes that the individual is at this point only 'discreditable':

*“when his differentness is not immediately apparent, and is not known beforehand....the issue is...that of managing information about his failing. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where” (Goffman, 1968:57).*

In purchasing medicine online, the fear of stigmatisation is more ‘real’ than enacted stigma, therefore information control is very important. The suggestion is that the impression management displayed by the research participants is not a response to medical authority, but rather a reaction to perceived societal attitudes on risky behaviour. This draws on the earlier discussion about the way the outcome of labelling behaviour deviant may be determined by personal attributes, real or imagined, rather than actual or presumed behaviour (Schur, 1979, 1980). The forum and survey data indicated that although people appeared less concerned about risks, they were aware of their connotations. Online medicine purchasing is potentially discreditable, as it could bring stigma related to disease or illness, or threaten reputation (how people might react or judge the behaviour) rather than the ‘risk’ of possible criminalisation.

People also described how using the Web allowed them to hide the purchasing from their friends and/or families. Virtual transactions allow for covert behaviour, which never needs to be divulged to others who might judge or express disdain. Therefore, the Web enables individuals to employ strategies for concealing actions that would lead to discrediting.

Those engaged in illegitimate purchasing i.e. prescription medicine without prescription, were compelled to undertake impression management in order to legitimise the deviant behaviour, and this involved the application of techniques of neutralisation (Sykes and Matza, 1957). Goffman gives us the idea of performance management, and this can be used with Sykes and Matza’s techniques of neutralisations to understand the different justifications people use. Yar (2014) used both these ideas to look at the narratives of disgraced sports celebrities. In my study I also combine these ideas.

Previous criminological research has explored the narratives of people who have offered public accounts of their transgressions in order to manage or deflect the

stigma associated with being negatively perceived in the offline world. This application of respectable deviance is an attempt to extend Yar's (2014) work on the narratives of 'fallen' celebrity sports stars that had been publicly exposed for doping and cheating. Yar (2014) drew upon Goffman's accounts of self-presentation and the management of stigma and 'spoiled identity'. His framework also built upon Sykes and Matza's (1957) concept of techniques of neutralization in order to investigate how individuals manage the consequences of being labelled a deviant. Denial of injury, denial of victim and appealing to higher loyalties are applied. Such techniques are, Yar demonstrated, employed to face, handle, resist and ultimately attempt to transcend the stigma that accompanies public shaming. However, there are some differences in method. Firstly, Yar's research was drawn from autobiographical narratives rather than interviews, survey and observational data.

Though interviews may also be viewed as types of autobiography, published autobiographies are publically available texts and the individuals involved are named and identifiable. Therefore, autobiographical accounts are clearly public performances, or what Yar (2014) referred to as "*the mass-mediated staging of self and identity for the consumption of readers*". The participants in my research were not, to my knowledge, celebrities or in the public eye and so their behaviour was unlikely to be accompanied by a high level of public visibility or interest. They did not necessarily construct accounts in relation to a mass public audience. Nonetheless, this approach was justified in my research, as I also encountered issues relating to performance and public and private perceptions, but on a smaller scale.

## **7.4. Techniques of Neutralisation in Online Medicine**

### **Purchasing**

This section will explain how online purchasers use neutralization as strategy to manage performance and identity. It draws upon Sykes and Matza's (1957) theory of techniques of neutralization, which they applied to the understanding of delinquent and youth behaviour. Some individuals engaged in the practice of purchasing online medicine, which is more controlled and therefore deemed more problematic;

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provide justifications in the form of techniques of neutralization (Sykes and Matza, 1957) to contend being labelled as deviant. Others appear to refrain from purchasing medicine online due to a reliance on a limited conceptualisation of how the activity is framed. There is tension present in the move from patient to consumer, whereby expertise and authority is challenged using the affordances of the Web.

Sykes and Matza highlighted how offenders recognise their guilt and use techniques of neutralization involving denials and appeals to overcome it. Similar techniques of neutralization are used to excuse or justify the purchasing of medicine from the Web, as demonstrated in Chapter Six. Denials are offered that claim the activity is related to 'normal' consumption such as shopping, whilst appeals are presented in the form of 'needs' for medication. Looking at each technique in turn, the interviews showed that some people deny responsibility by maintaining that what they are doing is as legitimate and authorised as other forms of online shopping or obtaining medicine offline.

*In effect I am doing the same actions as if a doctor had issued a prescription and I had gone to the chemist [Tina E25]*

However, there were some cases where individuals talked about responsibility and the risks involved in making online purchases of medicine.

Fiona spoke about how she would buy medicine for herself but not for her children.

*I will be quite risky with my own health, I will buy stuff online willy nilly, and take it, whatever. But I may not be the same with people who aren't me, like my children - I wouldn't dose them up with any old stuff. I assume my own risk, I can't assume theirs. It's like I'm more concerned about them than I am me [Fiona F7]*

She legitimised her behaviour by applying other techniques of neutralisation and downplaying the risks to herself, therefore applying denial of injury. This highlights how the techniques can be used together to offset guilt.

Another way to perceive the purchasing is that there is no victim as such, only the risk to the individual themselves, and so both the victim and injury can be denied.

Harm to others and wider society arising from the behaviour is discarded. The people purchasing medicine from the Web in my study were not hurting others, as it was a personal transgression.

*I understand the risks. There's no use blaming other people for your actions. The sellers don't force me to take the substance, I choose to take them [Anthony IM6]*

There were suggestions of othering in the data, where individuals dismissed the risk via notions of perceived expertise relating to their own capabilities and viewed other, less informed people as more vulnerable and susceptible to harm.

*I would say that for me personally it's a good thing for me that I can get my medication, but at the same time I can see that it can be a bad thing, but I try to be as thorough as I can because a lot of people can't, it is very easy for a company to hide within the Web and sell useless medications to vulnerable people [Rosie F22].*

*I think there are some very naïve people out there, I'm afraid, who use the Web, and they aren't always aware that they can quite easily buy things which aren't legal and which aren't healthy for you. And I think it's as much their fault as it is the people who sell stuff, but I also have to remind myself that not all people, in fact most people aren't as well read up on the Web as I am and they assume because a website looks good it must be good [Carl S11].*

These may be viewed as rhetorical devices that redirect attention away from the individual's own transgressions. Sykes and Matza (1957:668) describe it thus:

*"The validity of this jaundiced viewpoint is not so important as its function in turning back or deflecting the negative sanctions attached to violations of the norms. The delinquent has, in effect, changed the subject of the conversation in the dialogue between his own deviant impulses and the reactions of others; and by attacking others, the wrongfulness of his own behaviour is more easily repressed or lost to view".*

Condemning the condemners is also evident in this context in relation to the passing of judgment on health authorities and those who enforce the prescription

## *Respectable Deviance*

rules. People spoke negatively about the health industry and often viewed doctors as unnecessary gatekeepers. This was especially pertinent in the forums.

*My GP is extremely useless. He is honest about it though. He often says "Oh I don't know what that could be, I will just look it up on the internet." Well usually I already have. The only difference is I can't write my own prescriptions and I don't get paid a fortune. [F4 member f]*

*Everytime I go to the GP they either confirm I have what I think I have or say that I haven't and then when I go back a week later still with symptoms tell me I was right all along. I really cannot see the point of them beyond being a barrier between us and prescription drugs [F4 member a]*

For consumers, amidst the trajectory of discrediting information and stigmatising perceptions, the redirection of discussion towards the failing of others (i.e. the NHS, the US healthcare system, insurance etc.) serves multiple rhetorical purposes. First, it moves the focus of scrutiny away from the misconduct. Secondly, it recuperates and reinforces liability for that misconduct on to others, apportioning blame elsewhere. Lastly, the consumer is symbolically recast from a deviant to a victim of unjust treatment, who is worthy of sympathy because of their negative experience.

Law and regulation were also disregarded. In the interviews there were clear references to regulation and the desire to circumnavigate it in order to procure medicines that are unavailable in certain jurisdictions.

*I buy vitamin A, and they sell it over the counter in America, but you can only get it on prescription in this country, but you can buy it on Amazon because they import it from Thailand. I reached an age where I started to get one or two wrinkles and I thought I'm not putting up with this [Fiona F7]*

*I want to purchase items I cannot get in Luxembourg (where I live). [The Web] Seems to be the only and/or best place I can buy them. The US brand Tynelol Sore Throat medicine (which I was first given by friends just back from the USA & which works brilliantly for me) is just not available over here [Tina E25]*

Appealing to higher loyalties could also be a way of justifying deviant behaviour, as the rule of law has to be ignored for a greater purpose. In some cases, the higher



loyalties were manifested via perceptions of need. People stated that they especially needed to obtain medicine from the Web for a number of reasons such as availability, efficacy, avoidance of the doctor, ease and convenience, and the traditional methods of obtaining medicine were not suitable or viable in the circumstances. The suggestion is that some of those who purchase medicines online may not be as aware or even as concerned that they are 'breaking the rules' as they would be in the 'real world'. Yet there are individuals, particularly those who seek to buy prescription medicine and/or other substances, who knowingly transgress societal norms and who use techniques of neutralisation to justify their behaviour.

Maruna and Copes (2005), in their assessment of techniques of neutralization, saw the theory as an explanatory resource to explain offending amongst those who otherwise seem committed to the dominant normative system. The techniques are said to play a key part in temporarily deferring normative commitments that would otherwise impede law, as well as rule-breaking behaviour. However, my research concerns the strategies employed by individuals who are aware that the action of purchasing medicine online can be negatively perceived. In essence, techniques of neutralisation are employed in a manner that C. Wright Mills (1940:904) referred to as "*vocabularies of motive*" - the means through which "*actors ...vocalise and impute motives to themselves and to others*", essentially attempting to justify their actions. As Yar (2014) succinctly puts it, "*techniques of neutralization can be usefully treated as elaborations of those self-presentational strategies for managing stigma explored by Goffman and others*". People can use the Web to ensure their presentations are respectable, and do so using techniques of neutralizations. The Web opens up the purchasing of medicines, but some of this purchasing is potentially deviant. This deviancy can be and is managed via techniques of neutralization. However, the Web also offers the means of neutralizing, as it is the location of the performance.

#### **7.4.1. Distinctions between Justifications and Excuses**

What is noticeable in the narratives about purchasing medicine online is that although some people acknowledge that what they are doing might be perceived negatively, they attempted to present their actions positively. The purchasing is viewed as a good thing for the individuals concerned, despite the risky connotations. However, some presentations may be excuses rather than

justifications. Scott and Lyman (1968:47), in their study of accounts, which they define as “*statements made to explain untoward behavior and bridge the gap between actions and expectations*”, set out the differences between justifications and excuses. Extending Sykes and Matza’s denial of responsibility, they state that excuses are “*accounts in which one admits that the act in question is bad, wrong, or inappropriate but denies full responsibility*”. In contrast, justifications are “*accounts in which one accepts responsibility for the act in question, but denies the pejorative quality associated with it*”. The key distinctions are the recognition of the negative act and whether responsibility is assumed for it. These contrasting concepts also fit with the rest of the denials and appeals within Sykes and Matza’s techniques of neutralization.

The denials concerning online medicine purchasing as normal shopping are justifications, as injury is denied via the rejection of the act as ‘bad’. According to these denials, there is no more risk than when engaging in other online purchasing, and it appears that people are assuming responsibility for their actions. The narratives contesting medical expertise also appear to be justifications rather than excuses as responsibility is acknowledged; however, the act is presented as less reprehensible because people ‘know’ what they are doing. While the purchasing of medicine online might be dangerous for others, these people are informed, which negates the inappropriateness of the act. However, the appeals involving need are more suggestive of excuses, because in these cases the act of purchasing medicine online is recognised as negative; however, in needing to avoid the doctor or regulation, responsibility for the action is removed.

#### **7.4.2. Stages of Techniques of Neutralisation via the Pathway of Medicine Regulation**

The two previous chapters indicate that some people are aware that although buying certain medicines, even prescription-only medicine, are not necessarily illegal, their behaviour may be viewed negatively.

The techniques of neutralization in the accounts differ according to the type of medicine purchased. For example, consumers who had purchased OTC medicine did not feel the need to justify their purchase, as they saw their actions as authorised.

Even though they acknowledged that they were still at risk from counterfeit medicines, they were absolved of any legal repercussions. Minimal justifications were provided, and no techniques of neutralization were present.

*It does make me a little nervous, even when using a "safe" website, e.g. a Lloyd's Pharmacy, a Boots, etc, so again, I use it for relatively minor meds. I have looked into buying prescription meds online, but I can't convince myself it's safe [Esther E5].*

However, the purchasing of medicine that ordinarily requires a prescription was another story, especially when the consumer deliberately sought the medicine without a prescription. This behaviour required significant justifications. The techniques of neutralisation evident were denial of injury, denial of victim and appealing to higher loyalties. In the following example, the third is clear in the critique of doctors and their diagnoses.

*I normally obtain any medicines that I need by prescription from a Doctor. In the past, about 6 years or so ago I purchased medicines from the internet as my doctor was unwilling to prescribe these for me. I found information about B12 through my own personal research. The Doctor was unwilling to prescribe B12 because they said I had not been diagnosed with B12 deficiency [Olivia E19].*

*I found that I started to trust the doctors less and less at that point. I didn't really see the point of going to them anymore and the Web seemed to be the only other alternative that I could actually go to for medications because things like antidepressants are not available in supermarkets and if you go to a street pharmacist you have to show them the prescription. So the Web was the one way that I found round that [Rosie F22]*

In addition some substances fall within the grey area of regulation, such as NPS and unlicensed medicines/drugs, appeared to encourage more considerable attempts at techniques of neutralisation. Particular techniques of neutralisation used were denial of injury, denial of victim and appealing to higher loyalties, and were evident in the following critiques of licensed medicines and their effectiveness.

*[I purchase NPS] to try to treat my social anxiety. Medically approved drugs are ineffective in treating my SAD [Anthony IM6]*

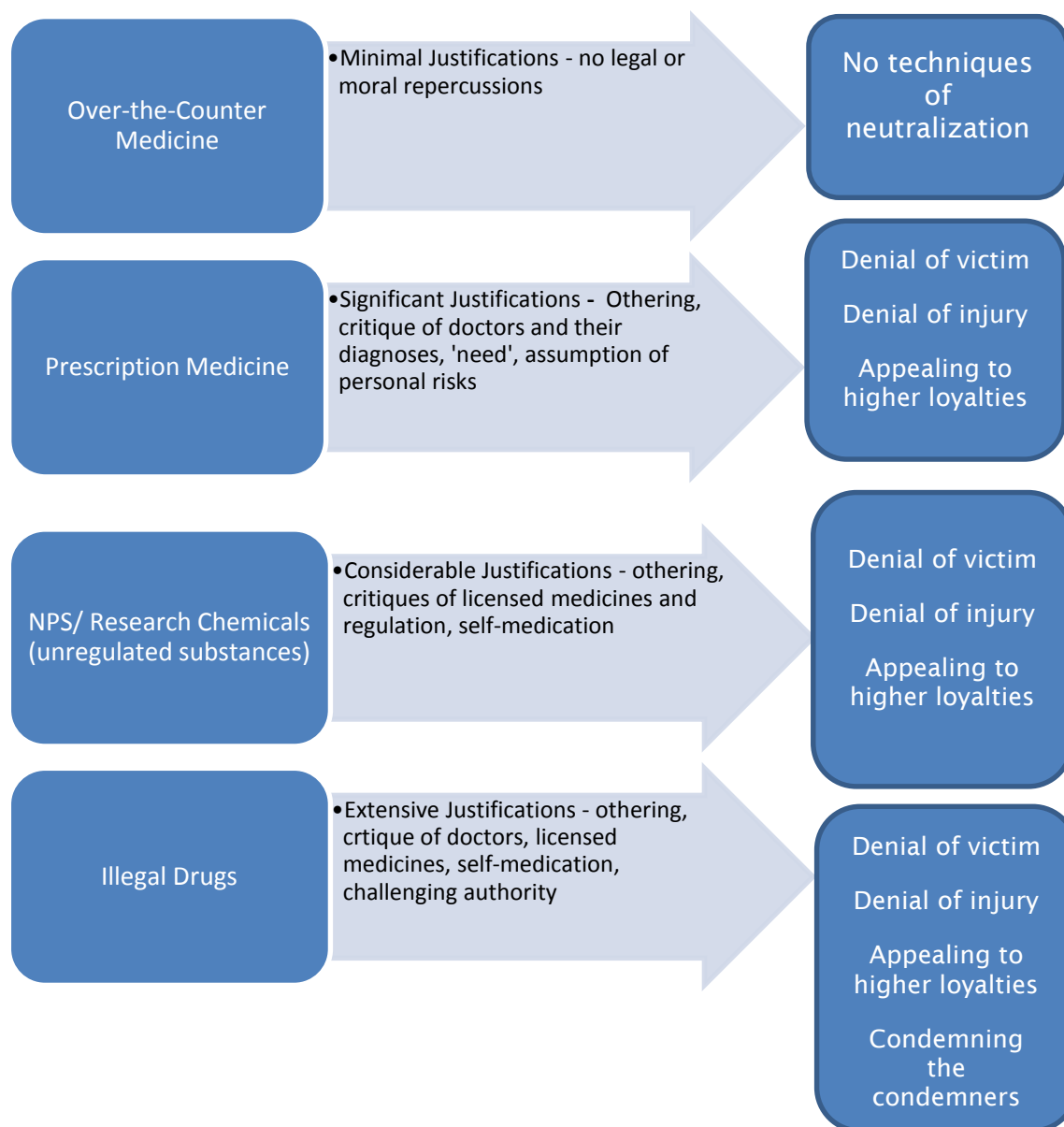
*You know what they [doctors] want to do, they want to put you on narcotics, which are, I mean I know cannabinoids are technically narcotics I guess, um however, they will dope you up bad, you can't work. They'll prescribe things like Aprazil, Xanax or um Cloptipin, any benzodiazepine like that. Will calm you down so you are like [mimics zombie] I gotta work and stuff, I'm just a little too, at nighttime I need to be able to wind down so basically that's what I use the cannabinoids for. Yeah anxiety, sleep [Ed S20]*

Finally, consumers who bought and consumed illegal drugs used multiple techniques of neutralization to justify their behaviour.

*I get drugs that the current medical establishment cannot prescribe and also because it can take a very long time to get an appointment with doctor here (Anywhere from a week to a year)...[ ]...medicine regulations favor companies that dispose of billions of dollars to test patentable medicines. The current regulations make it very difficult for unpatentable medicines to get approved because of profit incentives [Anthony IM6]*

Sykes and Matza's techniques of neutralization can be applied to the data on purchasing medicine online, but different techniques are applied depending on the type of medicine involved. Figure 20 offers a model outlining the continuum of techniques of neutralisation as applied to different types (classifications) of medicines and drugs.

Figure 20 The different techniques of neutralization for online medicine purchasing



I argue that buying medicine online encourages particular presentations of self (Goffman, 1959) and techniques of neutralisation are used to offset potential deviant labels and derogatory reactions (Sykes and Matza, 1957) associated with risk. In short purchasing medicines online appears to be a form of respectable deviance. Although consumers are not deliberately seeking to defy authority (this is

not the primary driver of online medicine purchasing), they are challenging the controls and structure of how medicines are administered. The Web affords them the ability to do this in a manner that allows them to retain a 'law-abiding' image (Kardstedt and Farrall, 2007). Regulation is circumnavigated rather than directly transgressed, an expressive, everyday act (Katz, 1988), which is an inevitable consequence of adapting to the 'risk society' (Beck, 1992).

## **7.5. Summary**

When talking about illegitimately and illegally buying medicines online, people demonstrate respectable deviance. They manage their performances and provide accounts in ways that attempt to legitimise their purchasing behaviour. A theoretical approach arising from the themes discovered via the data analysis has been developed. I have applied Sykes and Matza's concept of techniques of neutralisation to online behaviour and proposed a model (see Figure 20) to explain online presentations relating to online medicine purchasing. It conceptualises how online medicine purchasers, engaged in more 'risky' online medicine purchasing, view and manage their behaviour. Such an approach has not been utilised to understand online behaviour in this context before. It shows how a reinvention of traditional theories applied to the Web is useful in understanding online interactions and behaviours.

The identification of respectable deviance is important because it suggests that the Web has adapted and enabled deviant behaviours. In exploring the illegitimate obtaining of medicines, we can see that people purchasing medicine online are acting in unexpected ways. By carefully managing their presentations and offering justifications (usually associated with more acknowledged 'crimes'), those who have purchased medicine from the Web appear to be aware that their behaviour could be perceived as deviant. This behaviour is carefully managed in order to retain respectability and avoid stigma. The Web has created a new space for deviancy, and purchasing medicine online encompasses a respectable form of online deviance.

The Web is changing how people manage their healthcare choices and obtain medicine. In providing unrestricted accessibility to medicine, the Web has democratised consumerist opportunities and allows more people than ever before to engage in illegal and deviant activities. Nevertheless, the Web does not just provide spaces in which to engage in deviancy, it also enables people to manage how their actions are perceived- hence it affords respectable deviance





## **8. Conclusions and Further Implications**

This thesis has investigated online medicine purchasing and applied the concept of respectable deviance to understand this behaviour. Although there are regulations in place to govern the administration of medicines offline, people are able to bypass these when using the Web. In this thesis, I have sought a better understanding of this under-explored phenomenon via the thematic analysis of data obtained from web forums, quantitative and qualitative analysis of data procured from an online survey and qualitative semi-structured interviews.

In this concluding chapter, I will address the key contributions of this thesis, the first relates to the contribution to knowledge regarding the risks and opportunities in online medicine purchasing, whilst the second concerns the contribution to research in the online environment. The chapter is split into two sections. In the first section I revisit my research questions and describe how I have addressed them, outline the main findings of the previous chapters and explain what these findings and respectable deviance mean to the body of existing knowledge in this area. In the second section I discuss the wider research practices and implications of the study and provide a reflexive account of the process, considering how respectable deviance can also be applied to the researcher. I suggest further research that can be done as a result of this work and conclude by demonstrating how my findings have implications for practice and policy.

### **8.1. Revisiting the Research Questions and Objectives**

My research set out to explore how and why people buy medicines from the Web? I was particularly interested in the grey areas of purchasing prescription only medicines. As I began to explore the existing literature and problematise this topic this broad research question was refined and the following questions were formulated:

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1. What are the routes for online medicine purchasing?
2. What types of medicines are available for sale online and what types of websites sell these medicines?
3. Who is purchasing medicine online?
4. What drives online medicine purchasing and how can we better understand the practice?
5. How do people engaged in online medicine purchasing view their conduct once aware of it being constructed as risky and problematic by external agents?

The forum, survey and interview data addressed these questions. The findings extend the current body of knowledge on this issue. The interviews were intended to – and did – provide further knowledge about the ways people purchase medicine from the Web; however, they also uncovered something far more interesting, namely a new application of theories of respectable deviance. Some consumers aware that they are engaging in illegitimate online medicine purchasing manage how they present themselves talking about it and provide justifications traditionally associated with mitigating criminal and deviant behaviour. They react to a perceived negative label attached to online medicine purchasing, but online medicine purchasers are not classic deviants as the authorities have no power to actually criminalise them, and the behaviour is simply ‘risky’.

I will now outline how each of the research questions have been addressed.

### **8.1.1. What are the routes to online medicine purchasing?**

In supplying information, the Web fuels online medicine purchasing. The Web not only provides the means to purchase medicines, but also offers information about where and how to make such transactions online. People often find out about online medicine purchasing from the Web. One of the major routes to this type of purchasing is web browsing and online shopping. My studies have shown that people are discovering the availability of online medicines from sources unaffiliated with professional healthcare, suggesting that they are attempting to make their own personal healthcare choices. However, there are some people who claim that they turned to the Web to obtain medicines with their doctor’s knowledge and approval. There is also an

indication that people are driven by the need to find a particular medicine online that is not available by other means; this usually applies in the case of prescription medicines.

### **8.1.2. What are the types of medicines available for sale online and the types of websites that sell them?**

I have found that there are a plethora of medicines available to purchase on the Web, far more than is discussed in the literature. The Web does not reflect the dynamic nature of medicine regulation, and so there are many medicines and pharmaceuticals accessible even after they have been banned, or before they have been tested for safety and efficacy. Web users seem to be aware of this. Whereas some literature on purchasing medicine online has focused on lifestyle medicines as the main 'problem', my research indicates that other prescription medicines such as painkillers and antidepressants are often bought, which supports other claims of emerging trends (Forman, et al., 2006a; Raine et al., 2009). It appears that this purchasing is undertaken without prescriptions or medical authorisation. There are many unregulated spaces, providing access to a range of prescription and non-prescription medicines. Although there are online pharmacies that behave in a similar fashion to offline registered outlets and only sell authorised medicines, there are also plenty of websites that utilise the unique nature of the Web to engage in illicit practices.

The existing body of knowledge provides little insight into the overall phenomenon, but it does help to determine the extent of the issue. However, the focus on descriptive quantitative research provides limited evidence, and as this research has highlighted, relying on single-method approaches is problematic. My findings have allowed a more comprehensive understanding of online health behaviours. While previous studies have concentrated on specific medicines, such as lifestyle medicines, my research has extended the knowledge of attitudes and behaviours relating to the purchase of a wide range of medicines online.

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### **8.1.3. Who is purchasing medicine online?**

Vulnerable groups such as seniors and minorities have been suggested as the main purchasers of online medicine (Liang and Mackey, 2009). However, my study found no significant age difference among those who purchase medicine online. There were also no significant differences in gender and purchasing medicine online. Existing literature claims that the socioeconomically privileged are more likely to purchase medicine from online pharmacies (Littlejohn et al, 2005). Certainly, the demographics of my participants did represent high educational attainment and employment; however, this is not necessarily representative of all online medicine consumers, but rather my sample.

The research investigated Web users' views on online medicine consumption. This is exploratory work, which provided some information about the behaviour of the online medicine consumer. In accordance with Shaw and Baker (2004), those purchasing medicine online are identifiable as expert patients, who have unique demands for their healthcare after using the Web to source their health information.

I also identified presentations relating to what is respectable and what is not. I was not necessarily expecting to uncover these legitimization narratives within the data.

### **8.1.4. What drives online medicine purchasing and how can we better understand the practice?**

My findings have helped to contextualise an under-researched area of online behaviour. They have also helped in understanding the purchase of medicines, especially prescription medicine, from the Web. The data highlighted that those in 'need' of the medicine justify online medicine purchasing, where the Web provides the online means to obtain it. I have argued that opportunities and risks intertwined with consumerism and expertise are necessary concepts in appreciating the way people are buying medicine online. The Web has changed the way people are able to procure medicines (and drugs); it allows individuals to challenge healthcare expertise, and enables them to act as consumers as well as patients (Hardey, 2001) and to circumnavigate authorised healthcare channels. The Web ensures that healthcare expertise is not limited

to the professional as anyone can access the same knowledge and information, previously only available to the medical elite. Such knowledge and expertise is used to problem solve in people's everyday lives (Giddens, 1990). This creates a tension between experts and citizens as people challenge the role of regulatory bodies in making healthcare decisions for them. However, some people are aware of the potential connotations of their behaviour when purchasing medicines outside of regulatory controls, and provide justifications in order to offset any potential stigma.

Both purchasers and non-purchasers differentiate between legitimate and illegitimate online medicine purchasing. They show awareness of the various means of obtaining medicine, including unauthorised methods online. However, the majority of people who purchase medicine online indicate that they would prefer to retain links with authority and medical expertise, and continue to make the majority of their purchases from traditional (offline) sources. This in itself may be a response to the risks of purchasing medicine online.

#### **8.1.5. How do people engaged in online medicine purchasing view their conduct in light of it being constructed as risky and problematic?**

I took an existing framework of deviance theory and applied it to understand online medicine purchasing. The availability of medicines online makes it easier and more convenient for individuals to manage their healthcare choices. I have shown that one of the main reasons that people do not buy medicine online is that they do not need to do so. However, the accounts also demonstrate that people attempt to justify their behaviour when questioned. This is rather odd, and is in opposition to their claims that the practice is in the same category as other 'normal' online consumption. Furthermore, and most significantly, respondents were contradictory about their presentations relating to this particular issue. Some spoke about how they were compelled to hide their actions and keep their online medicine purchasing secret.

Throughout the research, respondents talked about the incentives to online medicine purchasing, which centred on convenience. However, they were also concerned about the risks associated with online medicine purchasing. People who had bought medicine online and those who had not shared similar

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attitudes towards risks. Both non-purchasers and purchasers appeared uninformed about medicine legislation, and viewed online medicine purchasing as a way to bypass expertise. However, non-purchasers were more concerned about the risks associated with counterfeit medicine. People who buy medicine online are willing to overlook the risks, and present narratives that display contested expertise and refer to personal experiences in order to respond to or downplay risk.

This thesis has uncovered a new form of online deviancy and has applied existing deviance theories concerning respectable deviance in a novel way.

## **8.2. Implications of ‘Respectable Deviance’**

I have shown how the concept of respectable deviance can be understood in three stages: firstly, that a particular behaviour (in this case online medicine purchasing, where it involves accentuated levels of illegitimacy) has been constructed as deviance, secondly, people are compelled to provide justifications for engaging in such behaviour (even if they themselves do not consider it deviant), and thirdly that presentation of self is carefully managed in order to maintain respectability. I have argued that when talking about purchasing medicine online, certain consumers engage in respectable deviance. They manage their performances and provide accounts that legitimise their purchasing. Sykes and Matza’s concept of techniques of neutralization has previously been utilised to understand online behaviour in the context of online piracy, but has also proved useful in understanding online interactions and behaviours in relation to purchasing medicine. I have demonstrated that more neutralisation techniques are deployed the more tightly controlled the medicine is.

Online spaces are difficult for the authorities to regulate and this opens up the pharmaceutical market. However, this is not a main consideration of those purchasing medicine online. It is not necessarily clear whether web spaces are trading legitimately, although some consumers indicate that they are aware of the difference between legitimate and illegitimate online medicine purchasing. They acknowledge different jurisdictional medicine regulations and how to

circumnavigate them online. Hence, challenging governance is used to justify online medicine purchasing. The Web has opened up a set of health behaviours that are impossible to regulate in the same way, as they are offline. This is due to the global accessibility of the Web and the opportunities it provides including expert information and consumerist possibilities. Challenging healthcare expertise is also a technique of justifying online medicine purchasing.

The Web simultaneously offers the opportunity to engage in deviance and manage performance. The Web has created new opportunities for the management of potentially deviant behaviour, and assists in the generation of respectable deviance. This research has demonstrated that some people who engage in the practice are aware of the way their actions may be construed negatively. This corresponds with criminological literature on people's management of their criminal and deviant behaviour via the use of justifications and legitimations. These contradictions reveal respectable deviance; however, purchasing medicines online is not necessarily an illegal act.

### **8.3. Wider Research Practice and Implications**

Using mixed methods has shown that respondents when discussing deviant behaviour present different 'selves'. This is a challenge to single-method studies. However, this research does not just provide an 'outsider' account, my exploration of online medicine purchasing also uncovered challenges within online research. The chapter now provides a consideration of my role within this process. This, along with the discussion of the ethical implications of this type of study could constitute a significant contribution to the growing body of knowledge on online research methods.

The concept of respectable deviance also applied to me as the researcher. My behaviour was constructed as 'problematic' and I then provided justifications and managed my performance to maintain my respectability. As well as the issues of credibility relating to whether I was an ethically sound online researcher (as discussed in Chapter Four) there were also further challenges to my respectability as a researcher during the interviews.

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### **8.3.1. Presenting Myself as the “Respectable” Researcher**

Reflecting on the ethical issues discussed in Chapter Four, I became aware that I underwent a process of justifying my actions and attempting to present myself as respectable in order to conduct my fieldwork. In developing my analysis it seemed my accounts were similar to presentations by forum members and survey and interview respondents. I faced challenges to my respectability as a researcher. In the next section I will review some key instances during the study and my reflections on these.

### **8.3.2. Challenges to my Respectability**

During the course of the interview process, I also had two minor negative experiences involving participants. These involved questions about bias in the survey, and I was also challenged about issues relating to security and the interview process. At the time this knocked my confidence, causing me to reassess myself as a thoughtful researcher and to doubt my abilities. Both participants had been contacted to take part in the interviews after completing the survey and providing me with their email addresses. It became apparent, after further communications with both participants that they had come to the survey after taking part in the Web Science MOOC course.

In the first scenario, the participant responded to my contact for interview request politely. He filled in the consent form and sent it back to me. After further requests from me to arrange the interview he sent me an email with numbered responses for each sentence. The email told of his experience obtaining a prescribed medicine using the Web. He was keen to stress that this was done with the advice of a doctor.

I asked to speak with him in order to understand more about the context of some of the points he had put on the email and to explore some of the issues he raised. He agreed to allow me to conduct the interview via email but asked for a copy of my interview guide sent to him first.

The participant was critical of the interview guide and went on to question my identity. He also went to great lengths to inform me of his extensive security experience and also revealed that he had been using a pseudonym and was not using a personal email. The provocative manner of his communication



reminded me of trolling, where individuals hide behind a mask of anonymity to deliberately provoke and antagonise. Being mindful of this, I decided to stop all interaction with them and I did not hear anything more from the participant.

In the second scenario, the participant requested that we conduct the interview via Skype and provided me with their Skype username and a suitable time to meet, but failed to attend two arranged meetings. The participant then asked to be interviewed using IM.

From the outset of the interview the participant's tone was guarded. Responses were short and to the point, and did not give me much information. He objected to some of the questions, specifically the ones, which addressed online medicine purchasing. He responded by challenging my research methods and accused me of sticking rigidly to an interview guide. He also presented himself in a similar manner to the other participant, by claiming he was an experienced researcher. The fact that issues were raised about the order of the questions also made me suspicious as to whether or not he was the previous participant who had viewed the interview guide. After this negative exchange I decided to terminate the interview.

### **8.3.3. Disclosing 'Self'**

My research also raised questions about reciprocation, namely how much or little researchers should reveal about their personal lives during research. I was pushed to reveal more about my 'self' when participants asked me personal questions about me. For example, one participant was interested to know whether I had ever taken any illegal substances. This put me in a difficult position; the participant appeared to be testing my attitudes towards drug use. Therefore I decided to disclose a personal story about being the victim of a 'drink-spiking'. I felt that this provided an example of experiencing the negative effects of drugs/alcohol without fully disclosing my attitudes to drug purchasing or abuse. This made me aware that I was asking people to share information about their lives that was difficult to reveal and I was also aware of my vulnerability as a researcher.

In some instances during the interviews, I was asked by participants to provide an opinion on the issue of buying medicine from the Web, namely whether or

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not I thought it was a positive or negative thing to do. I aimed to provide neutral answers rather than come down on one side completely. This was not always easy or comfortable, during this period, I found myself referring to Becker's (1967) paper *Whose Side Are We On?* for inspiration. As Becker points out, it is inevitable that research will have some political and personal influences; however, it is problematic to take sides as they arise. If feelings are made explicit, the sympathies of the researcher can bias the study (Becker, 1967). Instead, I used my theoretical and technical resources, as Becker suggested, to "*avoid the distortions*" (Becker, 1967:9), and field the allegations and misgivings that came my way.

Some personal disclosure was not under my control. It became apparent that some participants had done research about me before taking part. As a student and an online researcher, I have built up an academic web presence on sites such as Academia.edu, LinkedIn and Twitter, and having an unusual surname, my profiles were easily discoverable. My academic background in law and criminology led some of the participants to ask my opinions on medicines and drug purchasing, and some assumed that I would support prohibition and criminalisation; I had to challenge these assumptions in order to gain their trust and confidence in the study.

In the survey, respondents were invited to take part in follow-up interviews and to express their interest in doing so by providing an email address for future contact. In this comments field, some people challenged my motives for the study:

*I really hope this is an unbiased survey - not an attempt to demonize or criminalize people who have nowhere else to turn to. I'm an advocate against prohibition of all kinds*

*BTW if this survey is used in any way to hurt or shut down people who are helping people with no insurance and helping people with nowhere else to turn because doctors are more focused on overbooking patients under and misdiagnosing conditions/diseases then brushing them off when their 15 lousy minutes is up than you're evil and should be ashamed of yourself.*

These challenges were not predicted during the study design, and highlight how ethical issues during the research process extend beyond the usual considerations of consent, privacy, and anonymity.

#### **8.3.4. Exiting the Field**

Ethical quandaries were also extended in the building of relationships with my participants. I found that some people wanted to keep in touch after the study, and followed me on social media. I had to be careful not to cross the line in some cases and get too close; certainly there were occasions where I found myself almost in the role of a confidante rather than a researcher. Some individuals wanted to continue on the conversations after the study had finished. I had to find ways to distance myself. After the interviews had ended, I offered participants the opportunity to receive a transcript of our discussions (if the interview had not been via Skype IM or email, as there would already be a text document recorded in that case) and the opportunity to be contacted once the thesis was published. I felt that these were commitments that I could legitimately fulfil.

These discussions highlight that it is impossible to try to anticipate everything that might occur in research studies and that ethics is an ongoing social practice. Beyond the customary ethical considerations, online research also facilitates new challenges, both to the role of the researcher and to the research itself. The Web enables participants to find out more about the researcher and to make assumptions about their personal and professional 'selves', which can impact on the study. It also allows relationships beyond the research to continue easier, thanks to online communications such as email and social media. Therefore, researchers must be mindful about their online presentations and disclosures too.

I have also considered my role as a 'respectable' researcher when undertaking online research. I have shown (here and in Chapter Four) that though it is extremely challenging, it is possible to conduct ethical research into behaviour online. This type of research can be perceived as deviant both by those being studied and by institutional ethics committees. I experienced challenges to my work that required me to present justifications for my methods and legitimations for my research

### *Conclusions and Further Implications*

Chapter four addressed the key ethical considerations faced when undertaking online observational research. These are: the ambiguities in distinguishing between whether a Web space is public or private; whether or not it is necessary to obtain informed consent in public spaces; how to maintain privacy and confidentiality; and the importance of ensuring anonymity. This investigation may be useful in creating a framework to assist other online research projects, especially for those conducting research of a sensitive nature requiring covert methods. However, it is noted that any ethical considerations should be adapted to the context of the particular research study.

I argue that the researcher can engage in respectable deviance during the research process. At times I was viewed as the deviant, both by those under study and by my institutional ethics committee; however, this is necessary when engaging in deviant research. I have attempted to be as open and transparent about my research as possible. I have shown that even when the supposed best practice guidelines are followed, the results are not always positive or ethical. However, though significantly challenging, this thesis has demonstrated that it is possible to conduct ethical research into potentially deviant online behaviour. The position I adopted was a middle stance: the need for beneficial ethical application was deliberated and practised, but not to the extent that it impinged on the research itself. Though I followed disciplinary and institutional guidelines, I also allowed myself to respond to the context of the research environment.

#### **8.3.5. Future research possibilities**

The sample of people included in this research has some limitations. Behaviour was looked at from a micro level and it is accepted that the constraints of individual context and location may have affected narratives. It is not possible to generalise statistically to the wider population. However, I have offered a thematic analysis of purchasing medicine from the Web that contains analytical insights that are transferable for future research and allows us insight into a form of behaviour reconstructed by contemporary and digital affordances.

In my study, I set out to understand the reasons why people purchase medicine from the Web. I chose not to interview healthcare professionals, such as

pharmacists or doctors as the research focused on Web users and consumers of medicine online. Future studies might consider doing so to understand stakeholder perspectives. With the implementation of the European common logo in 2015 other research might consider consumer's awareness of it and whether it affects how they purchase medicine online.

## **8.4. Policy Implications**

This research can inform the understanding of the phenomenon of online medicine purchasing. This will be of relevance to the UK: Medicines and Healthcare products Regulatory Agency (MHRA). Current campaigns warning of the dangers and risks of online medicine purchasing are aimed at patients, and do not take into account the behaviour and attitudes of consumers. Agencies and policymakers should understand the needs of both in order to develop suitable interventions. Instead of trying to control people and stop them from purchasing medicine online, which is impossible due to the Web itself, policy makers should work in unison with consumers. More information and education is required about safe online medicine purchasing, rather than constructing it as a risky or deviant activity to engage in.

This thesis has demonstrated an innovative use of methods, and contributed to the growing body of knowledge of online research techniques. This knowledge could also be useful to society, as the implications of this thesis extend to policy research and the wider social sciences.

## **8.5. Conclusion**

In investigating online medicine purchasing this thesis has identified how the Web has created a new space for potentially deviant behaviour. I have shown how the purchase of medicine online is an example of a 'respectable' emerging deviant behaviour. This knowledge is useful not just to scholars of the criminology and sociology community, but to any researcher investigating online behaviour as it provides insight into how people manage themselves on the Web.

## *Conclusions and Further Implications*

This research has provided subjective accounts about online medicine purchasing, which demonstrate that the Web is indeed a threat to regulation. It is easy for consumers to ignore medicine legislation and bypass risk concerns. However, it is interesting that when they are asked about illegitimate online medicine purchasing certain challenges to authority are revealed as justifications. These justifications take on the form of techniques of neutralizations, which are usually applied to offset guilt, stigma and deviancy. However, from the consumer's perspective the action is about the ultimate goal of procuring the medicine, it is not driven by the motivation of challenging regulation, governance, and expertise. While authorities focus on problematic patients the Web challenges the pharmaceutical marketplace and causes tensions between governors and governed. It is not the individual consumer who is the problem; the threat appears intrinsic to the Web itself. The Web provides spaces for respectable deviance. It enables people to challenge the controls and structure of how medicines are administered, and provides opportunities to challenge hegemony. In order to understand how people respond to the unique risks and opportunities afforded in online medicine purchasing, the critical voice of criminology is essential. Medicine regulation is circumnavigated rather than directly transgressed via the 'network society' (Castells, 2000); this is an everyday act (Katz, 1988), which is an inevitable outcome of living in the 'risk society' (Beck, 1992).

This thesis has explored the world of online medicine purchasing and provided insight into how people account for this activity. I have presented a general description of online medicine purchasing using a framework regarding conceptual theories of deviant behaviour. The following key findings demonstrate how respectable deviance can be understood via online medicine purchasing:

1. The Web in providing information such as where and how to buy medicine online, fuels online medicine purchasing
2. There is a great deal more medicine available to buy online that is discussed in the literature
3. There are many unregulated spaces online offering access to a range of prescription and non-prescription medicines, providing the opportunity to bypass healthcare regulation

- These points inform how online medicine have been constructed as risky and deviant, but conflated with the 'hype' is the reality of the situation, law and authority are bypassed and there are risks to the consumer.

4. The Web is changing how people buy medicine - patients are consumers challenging professional expertise by drawing on their lay knowledge and experience procured from being web users - and is thus challenging traditional means of obtaining medicine

- This demonstrates how people respond to deviance with justifications. Such justifications utilise the opportunities in online medicine purchasing afforded by the Web.

5. People aware that engaging in behaviour breaking with accustomed practices (i.e. purchasing prescription/ unauthorised medicine from the Web) is viewed as risky, manage their performances with techniques of neutralization, specifically challenging governance and medical expertise.

- This highlights how people manage their presentations to maintain respectability. These challenge the risks involved in online medicine purchasing; and it is not clear whom or what is more at risk, the consumer or the hegemony of medicine regulators and health experts.

## *Conclusions and Further Implications*



# Appendices

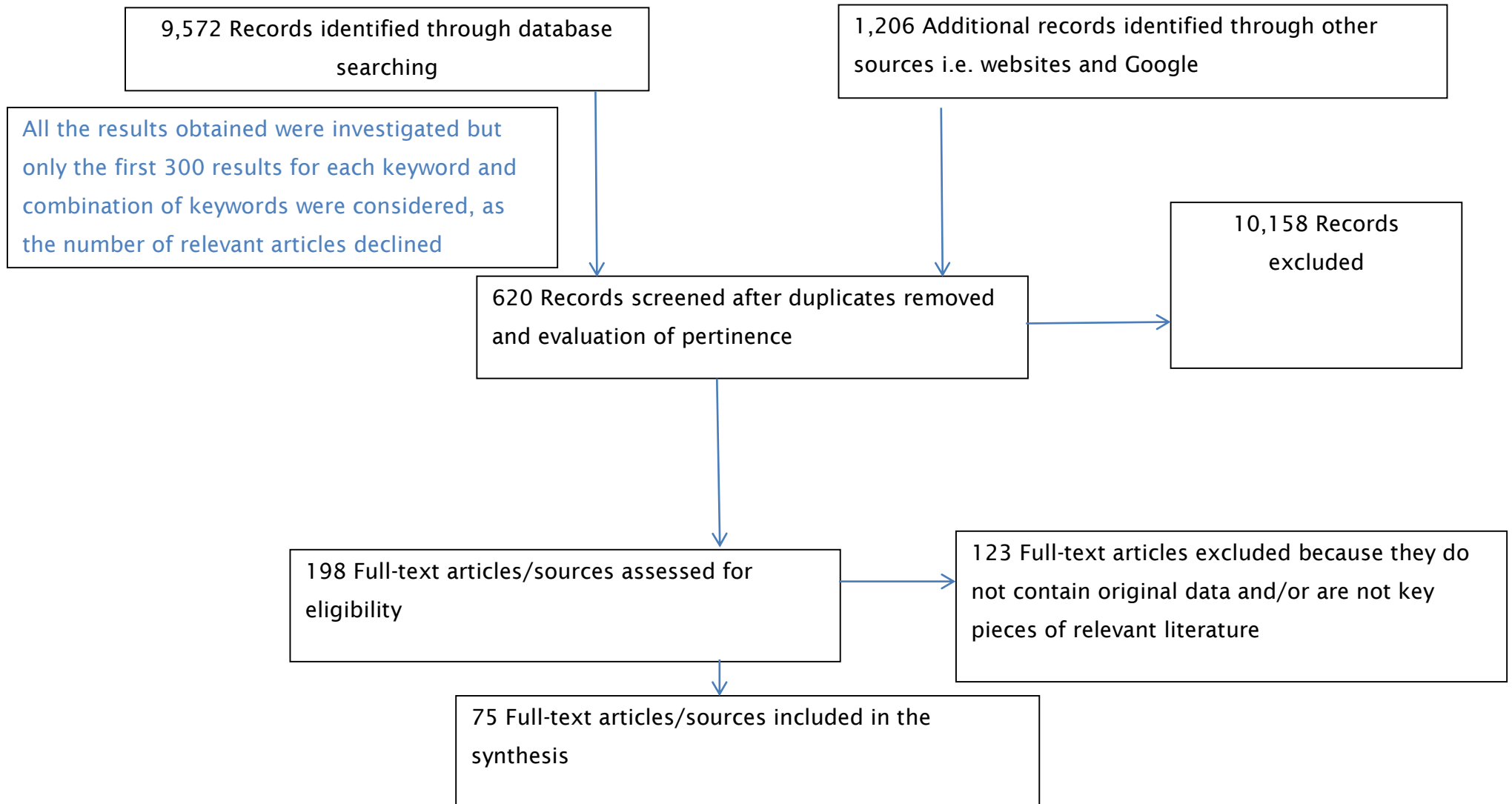


**Appendix 1 Keywords for Literature Search**

SEARCH A <b>Medicine or Prescription only Medicine or Drug# or Pharmaceutical#</b>
SEARCH B <b>Web or Internet or Digital or Technology or Computer</b>
SEARCH C <b>Purchasing or Buying or Consumer</b>
SEARCH D <b>Illegal or Illegitimate or Law or Statutory or Unauthorised or Regulation</b>
COMBINED SEARCH  results of A + B  results of A + C  results of A + B + C  results of A + B + C + D

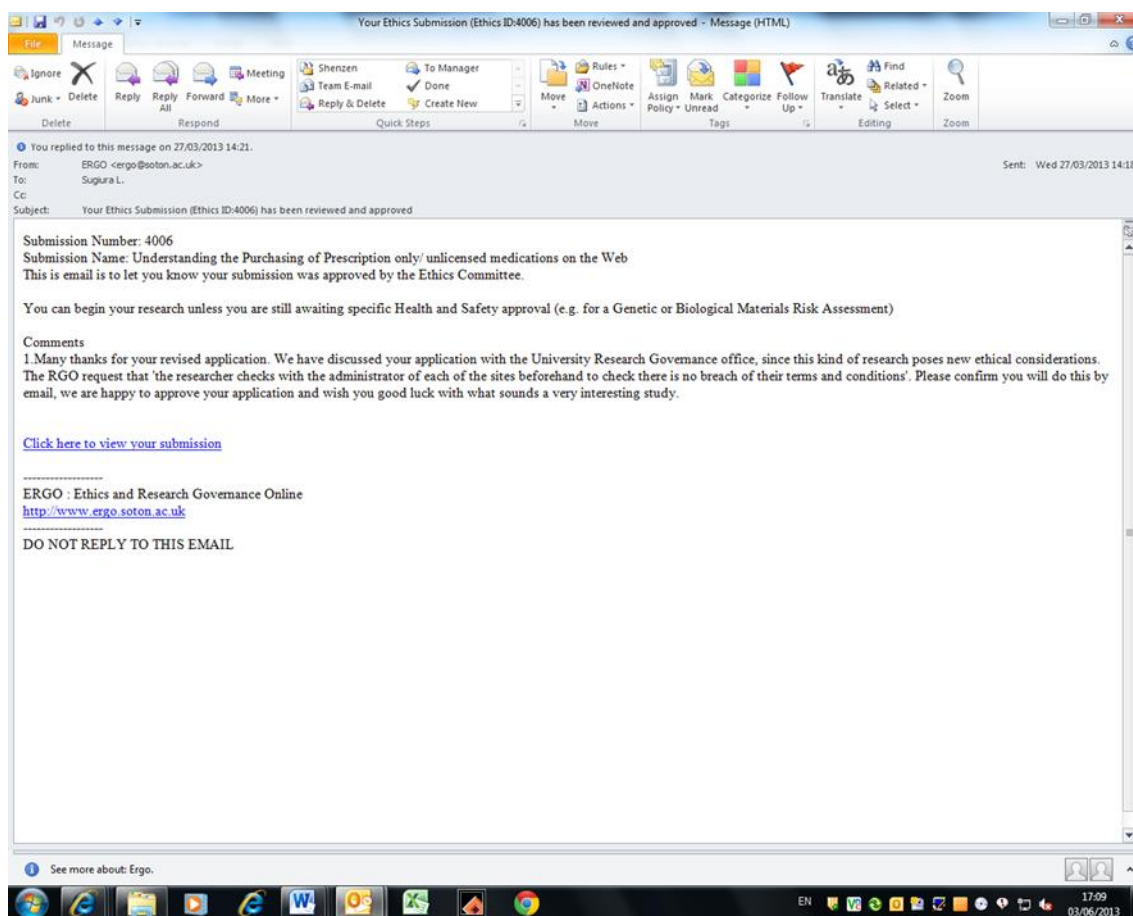


## Appendix 2 Algorithm Used for the Selection of the Final Papers





## Appendix 3 Ethical Approval







## Appendix 4 Ethical Approval for Resubmission





## Appendix 5 Initial Sampling of the Forums

Search terms	Results	Suitable forums
UK + health + wellbeing + forum	+ 9,810,000	5
UK + medicine + forum	+ 70,100,000	6
UK + asthma + forum	+ 8,850,000	3
UK + narcolepsy + forum	4	0
UK + breast cancer + forum	+ 12,800,000	5
UK + cholesterol + forum	+ 8,350,000	1
UK + skin conditions + forum	+ 66,600,000	3
UK + antibiotics + forum	+ 5,190,000	7
UK + anti-histamines + forum	+ 558,000	5
UK + anti -malarial + forum	+ 2,190,000	4
UK + arthritis + forum	+ 8,220,000	5
UK + erectile dysfunction + forum	171	8
UK + slimming + forum	+ 4,450,000	6
UK + painkillers + forum	+ 1,560,000	6
UK + hair loss + forum	+ 18,800,000	5
UK + steroids + forum	+ 9,240,000	7
UK + antidepressants + forum	+ 1,820,000	8



## Appendix 6 Initial Coding Frame for Forum Data

Themes and Codes	Three themes and subthemes	EXAMPLES
<p>Online Actions</p> <p>1.1. Purchased medicine</p> <p>1.2. Intention to purchase medicine</p> <p>1.3. Online research</p> <p>1.4. Offering advice/information</p> <p>1.5. Following advice/information</p> <p>1.6. Self-management</p> <p>1.7. Offering to sell</p>	<p><b>1. Influences on purchasing</b></p> <p><b>1.1 Positive shared experience</b></p> <p><b>1.1.1. Convenience</b></p> <p><b>1.1.2. Authenticity</b></p> <p><b>1.1.3. Effects</b></p> <p><b>1.1.4. Discretion</b></p> <p><b>1.1.5. Availability</b></p> <p><b>1.1.6. Empowerment</b></p> <p><b>1.2 Negative attitudes toward UK healthcare</b></p> <p><b>1.2.1. Invalid expertise</b></p> <p><b>1.2.2. Critical of government</b></p> <p><b>1.2.3. Unreliable</b></p> <p><b>1.2.4. Big Pharma</b></p> <p><b>1.3 Regulation</b></p> <p><b>1.4 Cost</b></p> <p><b>1.5 Online advertising</b></p> <p><b>1.6 Reputation</b></p> <p><b>1.7 Online research</b></p> <p><b>1.8 Interaction and advice from peers (offline)</b></p> <p><b>1.9 Conditions</b></p> <p><b>1.10 Frustration</b></p> <p><b>1.11 Desperation</b></p> <p><b>1.12 Embarrassment</b></p>	<p><i>"I have bought these items from some web sites in the past.</i></p> <p><i>The UK Government shut down most (or maybe all) of the UK sellers.</i></p> <p><i>Since the Government has done this, may 'official' chemists are charging extreme prices in this country (and much cheaper in other countries). Everything is inflated in the UK.</i></p> <p><i>I realise that some sites are now back up and running.</i></p> <p><i>Can anyone suggest any good suppliers of these products ?"</i></p> <p><i>"I am due to have yet another TSH blood test on Wednesday - and if that comes back as normal and my GP, yet again, refuses to prescribe me with any medication, I am thinking of resorting to purchasing the drugs from Europe online."</i></p> <p><i>"I am soooooooooooooooooo desperate to get hold of orlistat but am really struggling, there are some online pharmacies that stock it but the price is over £100 ! any ideas where i can get it ??"</i></p> <p><i>"LegitScript have been all over the pharmacy scene lately shutting down most sites. I buy my stuff still from <a href="#">Kamagra</a>"</i></p>

## Appendix 6

	<b>1.13 Self-management</b>	
<p>2. Offline Actions</p> <p>2.1. Interaction and advice from peers</p> <p>2.2. Interaction and advice from doctor</p>	<p><b>2. Influences against purchasing</b></p> <p><b>2.1. Negative shared experiences</b></p> <p>2.1.1. Risk</p> <p>2.1.2. Illegality</p> <p>2.1.3. Harm</p> <p>2.1.4. Fraud</p> <p>2.1.5. Counterfeit</p> <p><b>2.2. Positive attitudes toward UK healthcare</b></p> <p>2.2.1. Expertise</p> <p>2.2.2. Reliability</p> <p>2.2.3. Legitimacy</p> <p><b>2.3. Interaction and advice from doctor/healthcare professional</b></p>	<p><i>"I don't think you can even begin to fathom how much of a bad idea this is. I assume you live in the UK, a country with a free healthcare system. Why run the risks of harming yourself, and go to the expense of buying drugs online, when you can visit a GP and get the drugs from a reliable source, for free."</i></p> <p><i>"there are numerous problems with buying drugs on line</i>  <i>1. there is no assurance that you are actually receiving the drug you think you have purchased</i>  <i>2. drugs are Prescription Only for very good clinical reasons buying drugs off the internet , even if they come in authentic looking packets is just as risky as buying street drugs ..."</i></p>
<p>3. Positive shared experiences</p> <p>3.1 Convenience</p> <p>3.2 Authenticity</p> <p>3.3 Effects</p> <p>3.4 Discretion</p> <p>3.5 Availability</p> <p>3.6 Empowerment</p>	<p><b>3. Types of medicine/health conditions</b></p> <p>3.1. Slimming</p> <p>3.2. Erectile dysfunction</p> <p>3.3. (Bodybuilding) supplements</p> <p>3.4. Herbal/homeopathic remedies</p> <p>3.5. Antidepressants</p> <p>3.6. Antibiotics</p> <p>3.7. Legal highs</p>	

	<p><b>3.8. Painkillers</b></p> <p><b>3.9. Thyroid disease</b></p> <p><b>3.10. Benzodiazepines</b></p> <p><b>3.11. Diabetes</b></p> <p><b>3.12. IBS</b></p> <p><b>3.13. Asthma</b></p> <p><b>3.14. Menopause treatments</b></p> <p><b>3.15. Eczema</b></p> <p><b>3.16. Autism</b></p> <p><b>3.17. Sleep remedies</b></p>	
<p>4. <b>Ne</b> Negative shared experiences</p> <p>4.1. Risk</p> <p>4.2. Addiction</p> <p>4.3. Illegality</p> <p>4.4. Harm</p> <p>4.5. Fraud</p> <p>4.6. Misuse</p> <p>4.7. Counterfeit</p>		
<p>5. <b>P</b> Positive attitudes toward UK healthcare</p> <p>5.1. Expertise</p> <p>5.2. Knowledge</p> <p>5.3. Authenticity</p> <p>5.4. Reliability</p> <p>5.5. Legitimacy</p> <p>5.6. Authority</p>		

## Appendix 6

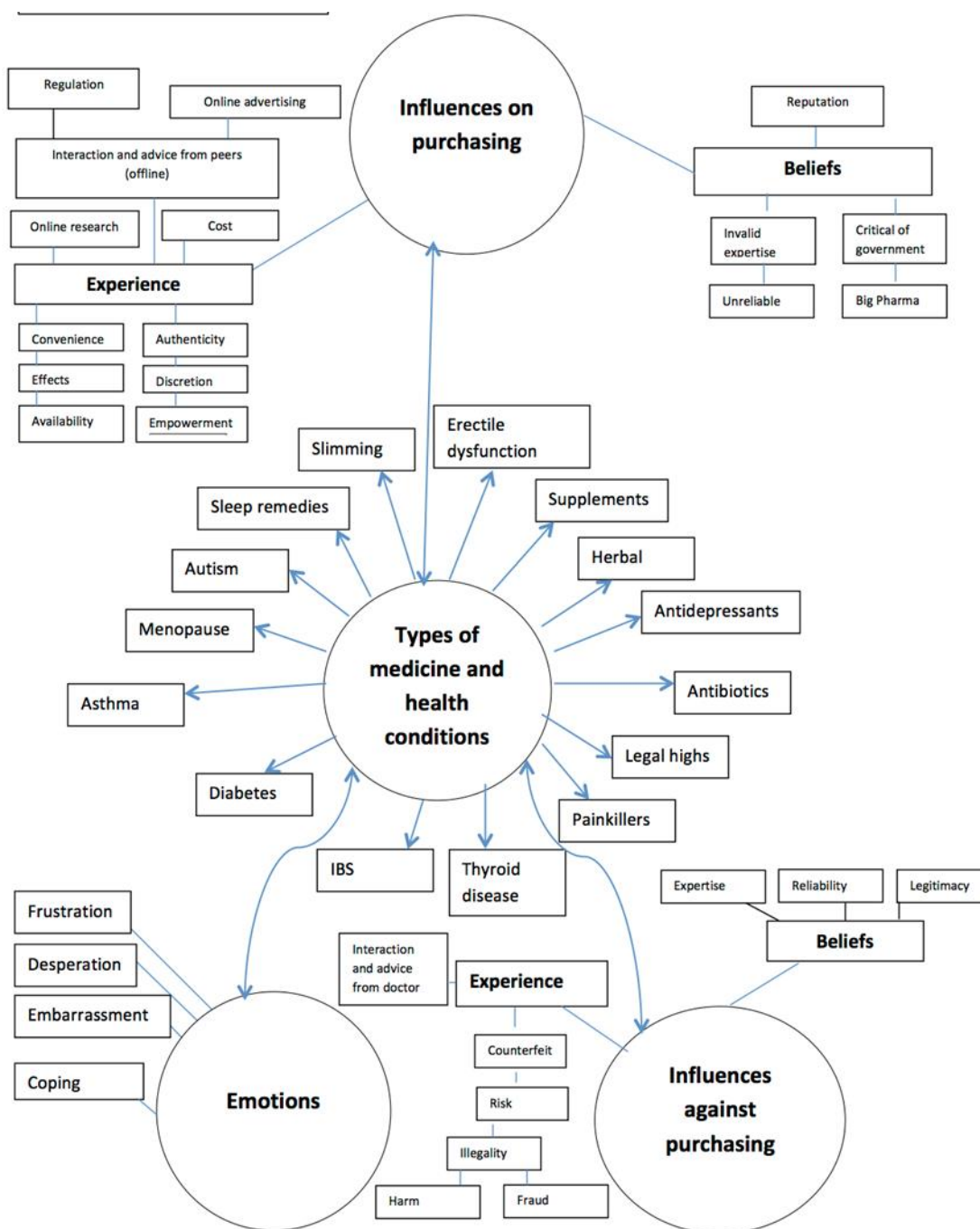
<p>6. Negative attitudes toward UK healthcare</p> <p>6.1. Invalid expertise</p> <p>6.2. Critique of Government</p> <p>6.3. Illegitimate</p> <p>6.4. Unreliable</p> <p>6.5. Big Pharma</p>		
<p>7. Considerations</p> <p>7.1. Jurisdiction</p> <p>7.2. Cost</p> <p>7.3. Regulation</p> <p>7.4. Advertisements</p> <p>7.5. Links</p> <p>7.6. Reputation</p>		
<p>8. Emotional states</p> <p>8.1. Frustration</p> <p>8.2. Desperation</p> <p>8.3. Embarrassment</p> <p>8.4. Uncertainty</p> <p>8.5. Body dissatisfaction</p>		
<p>9. Types of medicine</p> <p>9.1.1. Slimming</p> <p>9.1.2. Erectile dysfunction</p> <p>9.1.3. (Bodybuilding) supplements</p> <p>9.1.4. Herbal/homeopathic</p>		



remedies		
9.1.5. Antidepressant		
9.1.6. Antibiotics		
9.1.7. Legal highs		
9.1.8. Painkillers		
9.1.9. Thyroid disease		
9.1.10. Diabetes		
9.1.11. IBS		
9.1.12. Asthma		
9.1.13. Menopause treatments		
9.1.14. Eczema		
9.1.15. Autism		
9.1.16. Sleep remedies		



## Appendix 7 Initial Mind Map of the Forum Data





## Appendix 8 Pilot Testing for the Survey – Request

*I am currently piloting my survey and I would be really grateful if people could spare about 10 minutes of their time to have a go at filling it in for me. The survey can be found*

*here: <https://www.isurvey.soton.ac.uk/5625> Also if anyone has any feedback about the questions i.e. if anything seems ambiguous or any suggestions about the design please can you email me [ls3e10@soton.ac.uk](mailto:ls3e10@soton.ac.uk)*

*Thanks*



## Appendix 9 Examples of Survey Recruitment

Facebook Private Messages:

- Patient.co.uk –

Private Facebook message to Patient.co.uk :

- Conversation started July 2

7/2, 11:07am

[Lisa Sugiura](#)

Hi,

I have previously posted on your forums and on the facebook page about my research. I just wanted to ensure that it would be ok with yourselves if I posted the following message regarding a survey, on the facebook page (not on to the forums as I appreciate the sensitivity of that environment):

Hi, I'm a PhD student at the University of Southampton and I am undertaking an online survey into the purchasing of medicine from the Web. I am interested in finding out more about attitudes and experiences of people that purchase medicine from the Web or have thought about doing so, along with thoughts and opinions from people who have never purchased medicine from the Web.

I would be extremely grateful if people could spare the time to complete this survey, which can be found here (along with more details about the research)

<https://www.isurvey.soton.ac.uk/8264>

All responses will be anonymised and kept confidential, and participants are welcome from anywhere in the world.

The survey contains 42 questions and should take approximately 15 minutes to complete. I am also looking to conduct interviews following up on some of the survey questions. If you would like to take part in these please provide your email at the end of the survey where prompted.

Many thanks Lisa

7/2, 11:37am

[Patient.co.uk](#)

Hi Lisa Many thanks for your request – you have our permission to post details of your survey on our FB wall. Kind regards Stella

Appendix 9

7/2, 11:47am

[Lisa Sugiura](#)

Hi Stella,

Thank you very much



## **Appendix 10 Study Information Sheet for Survey Respondents**

### **Study Information Sheet - Online Survey**

*Understanding the purchase of prescription only medicine from the Web*

**Researcher name:** Lisa Sugiura

**Ethics reference:** 4006

My name is Lisa Sugiura. I am a PhD student of the Web Science Doctoral Training Centre, Faculty of Health Sciences, University of Southampton. I would like to invite you to participate in a research study titled "Understanding the purchase of prescription only medicine from the Web."

Before you decide if you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully. Please contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this information sheet.

### **What is the purpose of the survey?**

There are many different types of medicine available to buy from the Web. Some of these would ordinarily require a prescription from a health professional such as a doctor.

## Appendix 10

We are interested in finding out more about attitudes and experiences of that have purchased medicine from the Web or thought about doing so. The study will involve looking at health forum websites, a survey that will ask questions about buying medicine from the Web and some follow up online interviews.

This survey will ask about the purchasing of medicine online, to explore attitudes and experiences of purchasing medicine from the Web. The results will be used for a PhD thesis and may appear in future academic publications and outputs.

### **Why have I been chosen to do this survey?**

You have been chosen because:

You are visiting an online pharmacy website

### **Do I have to take part?**

No, taking part is voluntary. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time. If you decide not to take part you do not have to give a reason.

### **What will I be asked to do if I take part?**

If you decide to take part you will be asked to complete an online survey.

### **What are my responsibilities?**

If you are interested in taking part, please proceed with the survey.

**My contact details can be found at the end of this information sheet****What are the possible risks of taking part?**

There is the possibility that sensitive issues including health related topics will be discussed, individuals are reminded that they are participating in research which they have the right to withdraw from at any time.

**What are the possible benefits in taking part?**

There are no personal benefits for you in taking part. However, your participation in the study may help others and will contribute to our understanding of how and why people buy medicine online.

**What if there is a problem?**

If you have any complaints about the way you have been dealt with during the study or concerns about harm you might suffer these will be addressed. Please discuss with the researcher (Lisa Sugiura) in the first instance to see if the problem can be resolved. If you would prefer not to discuss with the researcher, you should contact Martina Prude, Research Governance Office at the University of Southampton, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 5058; Email: [M.A.Prude@soton.ac.uk](mailto:M.A.Prude@soton.ac.uk)). If you remain unhappy and wish to complain formally Martina Prude can provide you with details of the University of Southampton Complaints Procedure.

**Will my taking part in this study be kept confidential?**

Survey responses will be coded to ensure anonymity. All data will be securely stored for the duration of the research on password protected computers, and will only be available to the researcher and her supervisors, after which it will be permanently erased.

## Appendix 10

### **What will happen to the results of the research study?**

The results may be reported in academic publications or meetings, but no identifiable information will be used.

### **Who is organizing and funding the research?**

This study is being funded by the Engineering and Physical Sciences Research Council (EPSRC) Digital Economy Programme and organised by the researcher (Lisa Sugiura) as part of a PhD at the Web Science Doctoral Training Centre, University of Southampton.

### **Who has reviewed the study?**

This study has been reviewed and approved by the University of Southampton Research Governance department. It has been subject to ethical review by the Faculty of Health Sciences committee (ethics number: 4006 ).

### **What do I do now?**

Thank you for considering taking part in this research. **If you would like to take part, please continue to the survey.**

**(<https://www.isurvey.soton.ac.uk/8264>)**

### **Identification of researcher**

If you have any questions or concerns about this research, please contact:

Lisa Sugiura

Faculty of Health Sciences  
University of Southampton  
Building 67,E2013  
Highfield Campus

SO17 1BJ

Tel: + 44 (0) 23 8059 8478

**Email:** [ls3e10@soton.ac.uk](mailto:ls3e10@soton.ac.uk)

Academic Supervisor: Professor Catherine Pope

**Telephone:** (023) 8059 8293

**Facsimile:** (023) 8059 8308

**Room Number:** 67/E4019

**Email:** [C.J.Pope@soton.ac.uk](mailto:C.J.Pope@soton.ac.uk)

Academic Supervisor: Dr Craig Webber

**Room Number:** 58/4065

**Email:** [C.Webber@soton.ac.uk](mailto:C.Webber@soton.ac.uk)



## Appendix 11 SPSS Variables

### SPSS Variables

1. Bought
2. Whynot1
3. Whynot2
4. Whynot3
5. Whynot4
6. Whynot5
7. Whynot6
8. Whynot7
9. Whynot8
10. Whynot9
11. Whynot10
12. Where1
13. Where2
14. Where3
15. Where4
16. Where5
17. Howoften
18. Requirement1
19. Requirement2
20. Requirement3
21. Requirement4
22. Requirement5

## Appendix 11

23.Requirement6

24.Worried1

25.Worried2

26.Worried3

27.Worried4

28.Worried5

29.Worried6

30.Worried7

31.Worried8

32.Worried9

33.Belief1

34.Belief2

35.Belief3

36.Belief4

37.Belief5

38.Lastmed

39.Cost

40.Usuallyobtain1

41.Usuallyobtain2

42.Usuallyobtain3

43.Usuallyobtain4

44.Usuallyobtain5

45.Usuallyobtain6

46.Usuallyobtain7



47.Age

48.Gender

49.Ethnicity

50.Location

51.Employment

52.Education

53.Maritalstatus



## Appendix 12 Codebook of the Survey Data

- This data is setting the context of the situation – the “what” question: what does this data tell us/what can we know about the buying of medicine from the Web?

### Outline:

1. Have you bought medicine from the Web? Three groups – Yes, No, Non-disclosure (ND)
2. Yes group data
3. No group data
4. Non-disclosure data – is it possible to deduce from their answers whether they have bought medicine online?
5. Cross-comparisons of the groups

Trends to look out for (based on the observations of the forums):

Types of medicines –

Q 1.1a (for the Yes respondents) Which types of medicines have you bought online? (Qualitative responses?)

Q. 3.3 (Section available to all respondents) [Thinking back to the last time you acquired medicine] What was the name of the medicine? (Qualitative responses?)

Influences to purchasing –

Q. 1.1a (for the No respondents) Why haven't you bought medicine online?

Q 1.1e (for the Yes respondents) When buying medicine online are you ever worried about the following?

## Appendix 12

The ND bypassed this question

Experiences

Availability

Resourcing information

Authenticity

Cost

Risks

Convenience

Safety and quality

Attitudes and opinions –

Q. 1.2 The following statements concern your beliefs about buying medicine from the Web. Please click on the option that best represents your belief for each statement

(Section available to all respondents)

Structure of healthcare – prescriptions

Regulation – I might be breaking the law

Availability of medicines to buy online

Authenticity of medicines online

Safety of medicines online

How questions (context) –

Q. 1.1.b (For the Yes respondents) How often do you buy medicine online?

Q 1.1c (For the Yes respondents) When you purchase medicine online have you ever been asked for/to participate in any of the following

Q.3.1 (Section available to all respondents) [Thinking back to the last time you acquired medicine] Where did you get the medicine from?

Q. 3.2 (Section available to all respondents) [Thinking back to the last time you acquired medicine] What was this medicine used for? (Qualitative responses?)

Q. 3.4 (Section available to all respondents) [Thinking back to the last time you acquired medicine] How much did you pay for the medicine?

Q. 4.1 (Section available to all respondents) Where do you usually get your medicines from?



## Appendix 13 Email for Follow-Up Interview

**From:** Sugiura L.

**Sent:** 23 September 2013 15:43

**To:**

**Subject:** Interview re: Buying medicine from the Web Survey

Thank you for completing my survey on buying medicine from the Web <https://www.isurvey.soton.ac.uk/8264> and agreeing to be contacted for the purpose of having an interview.

I have attached a study information sheet which provides all the information about the study and what you can expect from the interview. If you are happy to participate in an interview with myself please can you electronically complete and sign the consent form that I have also attached, and email it back to me. Please can you also indicate whether you would prefer to have the interview conducted via Skype or email/ IM.

Many thanks and best wishes

Lisa

Lisa Sugiura  
Web Science PhD Student  
Faculty of Health Sciences  
University of Southampton  
Building 67,  
Highfield Campus  
SO17 1BJ  
Tel: + 44 (0) 23 8059 8478  
Email: [ls3e10@soton.ac.uk](mailto:ls3e10@soton.ac.uk)





## **Appendix 14 Study Information Sheet for Interview Participants**

*Understanding the purchase of medicine from the Web*

**Researcher name:** Lisa Sugiura

**Ethics reference:** 4006

My name is Lisa Sugiura. I am a PhD student of the Web Science Doctoral Training Centre, Faculty of Health Sciences, University of Southampton. I would like to invite you to participate in a research study titled “Understanding the purchase of medicine from the Web.”

Before you decide if you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully. Please contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this information sheet.

### **What is the purpose of the study?**

There are many different types of medicine available to buy from the Web. Some of these would ordinarily require a prescription from a health professional such as a doctor.

We are interested in finding out more about attitudes and experiences towards purchasing medicine from the Web. The study will involve looking at health forum websites, a survey that will ask questions about buying medicine from the Web and some follow up online interviews.

Interviews will be conducted with a small number of survey participants to obtain further information about the opinions from consumers. The findings of

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the research will form the basis of a PhD thesis and any associated publications.

### **Why have I been chosen?**

You have been chosen because:

You have taken part in the survey and indicated that you are willing to be interviewed. I would like to interview between 25-30 people. If more than this number agrees I may select participants using analysis of the survey. Both participants and those not chosen to be interviewed will be notified within four weeks of completion of the survey.

### **Do I have to take part?**

No, taking part is voluntary. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time. If you decide not to take part you do not have to give a reason.

### **What will I be asked to do if I take part?**

If you decide to take part I will contact you by email to arrange a convenient time for the interview to take place.

### **The interview**

I would like to have the opportunity to talk to you in more depth about some of the topics covered in the survey. This will include discussion of choices when buying medicine online, the reasons and motivations for doing so, and any problems or difficulties you may have encountered if you have purchased medicines using the Web. The interview will take place at a time and date that is convenient to you, either by Skype or email.

During the interview you will be asked to talk about your opinions, attitudes and experiences about purchasing prescription medicine online. This discussion will last no longer than 40-60 minutes. **The discussion will be saved and recorded (if using Skype) and notes will be taken during the session.** The interviewer will be the researcher (Lisa Sugiura).

### **What are my responsibilities?**

If you are interested in taking part in the interview, I would be very grateful if you would contact me by email. I will then contact you to answer any queries you may have and to discuss suitable arrangements for the interview.

After the study has been completed you will receive a debriefing. This will involve the researcher checking that you are happy with how the study was conducted, what will be done with the data and that you are aware of your rights as a participant.

### **My contact details can be found at the end of this information sheet**

### **What are the possible risks of taking part?**

There is the possibility that sensitive issues including health related topics will be discussed, individuals will be reminded that they are participating in research which they have the right to withdraw from at any time and/or will be directed to suitable resources.

Every effort will be made to avoid upsetting you; however, there is a possibility that some of the things discussed might be upsetting for you. If you were to become upset you would be asked whether or not you wanted to continue with the interview.

**What are the possible benefits in taking part?**

There are no personal benefits for you in taking part. However, your experience is very valuable; your participation in the study may help others and will contribute to our understanding of how and why people buy medicine online.

**What if there is a problem?**

If you have any complaints about the way you have been dealt with during the study or concerns about harm you might suffer these will be addressed. Please discuss with the researcher (Lisa Sugiura) in the first instance to see if the problem can be resolved. If you would prefer not to discuss with the researcher, you should contact Martina Prude, Research Governance Office at the University of Southampton, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 5058; Email: [M.A.Prude@soton.ac.uk](mailto:M.A.Prude@soton.ac.uk)). If you remain unhappy and wish to complain formally Martina Prude can provide you with details of the University of Southampton Complaints Procedure.

**Will my taking part in this study be kept confidential?**

I will not reveal that you have taken part in this study, or what you have said to anyone. The only exception to this is if you were to tell me that you or another person was at risk of harm. The term harm covers all harmful behaviour, for example:-

- physical harm
- psychological harm causing fear, alarm or distress
- behaviour which adversely affects property, rights or interests (for example, theft, fraud, embezzlement or extortion)
- self-harm
- neglect

In this case I would be duty bound to share this information with an appropriate authority such as the social work department and/or the police.

Confidentiality will be maintained by means of coding conducted by the researcher to ensure anonymity. All data will be securely stored for the duration of the research on password protected computers, and will only be available to the researcher and her supervisors, after which it will be permanently erased. Data containing verbatim quotations may be used within the PhD thesis and any associated publications, however any identifiable details will be changed or omitted.

#### **What will happen to the results of the research study?**

The results may be reported in professional publications or meetings, but you will not be identified by any name, pseudonym or username provided to the researcher. You may like to receive a copy of the summary of the research, and can indicate this when you participate.

#### **Who is organizing and funding the research?**

This study is being funded by the Engineering and Physical Sciences Research Council (EPSRC) Digital Economy Programme and organised by the researcher (Lisa Sugiura) as part of a PhD at the Web Science Doctoral Training Centre, University of Southampton.

#### **Who has reviewed the study?**

This study has been reviewed and approved by the University of Southampton Research Governance department. It has been subject to ethical review by the Faculty of Health Sciences committee (ethics number: 4006).

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### **What do I do now?**

Thank you for considering taking part in this research. **If you would like to take part, please contact me via email at [ls3e10@soton.ac.uk](mailto:ls3e10@soton.ac.uk)**

### **Identification of researcher**

If you have any questions or concerns about this research, please contact:

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## Appendix 15 Interview Guide for Non-Web Purchasers

Thank you so much for agreeing to be interviewed, the aim of this study is to find out more about the buying of medicines from the Web. Before we proceed I would just like to confirm that you are happy to go ahead with the interview and for it to be recorded?

My questions are designed to get a sense of what you think about medicines, their availability to purchase online, and your experiences. I'm going to ask you about where you usually get your medicines from. It would be really helpful if from the outset we could be clear about the types of medicines we are talking about – so whether they are regular medicines for longstanding illnesses or for infrequent conditions. I don't need to know all the details about any illnesses or conditions, I really just want to learn about how you get the medicines you need then I'll talk more about why you don't use the Web.

0. Before we start, could you just remind me again:

Your location

Your age group

1. May I ask how you came across the survey?

2. And why did you choose to fill in the survey?

3. Where do you usually obtain your medicines from?

3.a. Why do you choose to obtain your medicines from there?

3.b. How satisfied are you with how you currently obtain your medicines?

4. Where did you obtain your most recent medicine?

4.a. What was the medicine?

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4.b. Did you need a prescription for this medicine?

5. Where is the first place/ or whom do you turn to for medical advice?

5.a. Why is that the first place/ person?

5.b. (If not already mentioned) Have you ever looked for health information online?

6. Do you do any online shopping?

6.a. What sorts of items do you buy online?

6.b. Which websites do you use?

6.c. Are you concerned about credit card fraud/ identity theft/ fraudulent online sellers at all?

7. Are you a member of any social networking sites/ online forums – such as Twitter, Facebook, any online support groups?

7.a. Please can you elaborate?

8. Have you ever received emails/ seen advertisements online for medicine?

8.a. What is your opinion about such emails/adverts?

9. How informed do you feel about the types of medicines online?

9.a. Please can you elaborate?

10. How informed do you feel about where to buy medicines online?



10.a. Please can you elaborate?

11.How informed do you feel about medicine regulation?

11.a. Please can you elaborate?

12.Do you have any experience of purchasing medicine from the Web (this could be personal or knowledge of others experiences)?

12.a. Please can you elaborate?

13.What are your reasons for not purchasing medicine from the Web?

13.a. Please can you elaborate?

14.Do you have any concerns about obtaining/ buying medicines offline?

15.Do you think consumers are adequately protected when buying medicine online?

15.a. What more could be done?

16.Is there anything that could make you consider buying medicine from the Web?

17.Is there anything else that you would like to tell me or that you think I should know?



## Appendix 16 Interview Guide for Web Purchasers

Thank you so much for agreeing to be interviewed, the aim of this study is to find out more about the buying of medicines from the Web. Before we proceed I would just like to confirm that you are happy to go ahead with the interview and for it to be recorded?

My questions are designed to get a sense of what you think about medicines, their availability to purchase online, and your experiences. I'm going to ask you about where you usually get your medicines from. It would be really helpful if from the outset we could be clear about the types of medicines we are talking about – so whether they are regular medicines for longstanding illnesses or for infrequent conditions. I don't need to know all the details about any illnesses or conditions, I really just want to learn about how you get the medicines you need then I'll talk more about the Web.

0. Before we start, could you just remind me again:

Your location

Your age group

1. May I ask how you came across the survey?

2. And why did you choose to fill in the survey?

3. Where do you usually obtain your medicines from?

3.a. Why do you choose to obtain your medicines from there?

3.b. How satisfied are you with how you currently obtain your medicines?

4. Where did you obtain your most recent medicine?

4.a. What was the medicine?

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4.b. Did you need a prescription for this medicine?

5. Where is the first place/ or whom do you turn to for medical advice?

5.a. Why is that the first place/ person?

5.b. (If not already mentioned) Have you ever looked for health information online?

6. Do you do any online shopping?

6.a. What sorts of items do you buy online?

6.b. Which websites do you use?

6.c. Are you concerned about credit card fraud/ identity theft/ fraudulent online sellers at all?

7. Are you a member of any social networking sites/ online forums – such as Twitter, Facebook, any online support groups?

7.a. Please can you elaborate?

8. Have you ever received emails/ seen advertisements online for medicine?

8.a. What is your opinion about such emails/adverts?

9. How informed do you feel about the types of medicines online?

9.a. Please can you elaborate?

10. How informed do you feel about where to buy medicines online?

10.a. Please can you elaborate?

11. How informed do you feel about medicine regulation?

11.a. Please can you elaborate?

12. Can you tell me about your experiences of purchasing medicine from the Web (this could be personal or knowledge of others experiences)?

12.a. Please can you elaborate?

13. What are your reasons for purchasing medicine from the Web?

13.a. Please can you elaborate?

14. How did you know where to go to purchase the medicine, for example which website/s to visit?

15. Approximately how often do you/ have you bought medicine from the Web?

16. Will you continue to buy medicine from the Web?

17. What types of medicine have you purchased from the Web?

18. Approximately how much do you spend each time on medicine from the Web?

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19. Did the website/s require a prescription/ consultation/ questionnaire to purchase the medicine?

19.a. (If none of the above) why did you purchase the medicine regardless?

20. Did you seek any offline medical advice (i.e. from a qualified healthcare professional) before making the purchase online?

21. Did you seek any online medical advice (i.e. from a web pharmacist/ NHS direct website/ Blogs/ health forum etc. before making the purchase online?

22. Are you aware of the website's location (e.g. country that it is based in) when you buy medicine online?

23. How quickly do you receive the medicine when you order online?

24. Are you satisfied that the medicine you have bought online is correct e.g. has the right ingredients etc.

25. Have you ever experienced any side effects from medicines bought online?

26. Do you have any concerns about buying medicine from the Web?

27. Do you have any concerns about obtaining/ buying medicines offline?

28. Do you think consumers are adequately protected when buying medicine online?

28.a. What more could be done?

29. Is there anything else that you would like to tell me or that you think I should know?





## Appendix 17 Coding Frame for the Interview Data

1. **Medical Expertise** – Accept or reject – if accept it can help to explain why some people choose not to buy medicine from the Web and follow the traditional healthcare route. If people reject it they may turn to the Web (relying on lay expertise) as an alternative source for medicine).

1.1. Trust (linked with respect and belief)

1.1.1. Responsibility (to provide good care and service to patients/ the public)

1.1.2. Advice (to provide legitimate information and education to patients/the public)

1.1.3. Reputation (linked with professional – medical professionals are registered and have the requisite training and knowledge to provide products that have been properly tested for safety and efficacy. The public can be confident that their health is protected by suitable safeguards based on medical evidence.)

1.1.4. Patient confidentiality (personal information is secure)

1.2. Experience (with medical professionals) – linked to knowledge (this can be positive or negative – which may impact on individual's attitudes and beliefs towards healthcare.)

1.2.1. Familiarity (a personal relationship has been built up, it is what the individual has always known, relied on)

1.2.2. Communication (Easy to converse with doctors/pharmacists etc., obtain access to them via appointments)

1.2.3. Sympathetic (Patients have been treated well and found their doctors understanding)

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- 1.2.4. Diagnosis (Patient's conditions have been properly recognised and treated)
- 1.3. Controls (these may be viewed as [un]necessary for the secure administration and consumption of medicine)
  - 1.3.1. Gatekeepers (Doctors are barriers to medicine and access to healthcare choices)
  - 1.3.2. Legislation (Medicine regulation provides restrictions on what is available to patients and consumers)
2. **Lay Expertise** – Accept or reject – if accept it can help to explain why some people choose to buy medicine from the Web. This challenges the dominant role of the Doctor/pharmacist as the established route to healthcare and medicine. If reject, individuals may rely on the entrenched view that medical expertise is the appropriate method of obtaining medicine.
  - 2.1. Trust (linked with belief – putting faith in)
    - 2.2.2. Research (the skills to obtain and educate oneself about medical information – from the Web or other sources)
    - 2.2.3. Advice (from peers – online and offline)
    - 2.2.4. Responsibility (to be liable for one's own actions)
  - 2.2. Experience (personal experiences have helped to shape individual's beliefs in their own knowledge of healthcare and medicine - this may or may not be empowering)
    - 2.2.1. Encouragement (influence from others who are not healthcare professionals)
    - 2.2.2. Support (from others not healthcare professionals)

- 2.2.3. Relatable (others have had similar experiences or the individual recognises something from a past experience they have had)
- 2.2.4. Instincts (relying on common-sense approaches to make healthcare decisions)
- 2.3. Practices (Actions that are outside of the conventional [regulated] methods of obtaining medicine and access to healthcare – some may suggest deviancy. The Web (especially the “dark web”, may factor as a place to assist such behaviour)
  - 2.3.1. Buying medicine whilst abroad (to take into another country where that medicine is unavailable)
  - 2.3.2. Avoiding taking any medicine/having treatment at all (would rather let “nature take its” course with illnesses)
  - 2.3.3. Use of alternative remedies (herbal treatments etc.)
  - 2.3.4. Sharing medicines (if prescription medicine = misuse)
  - 2.3.5. Self-medication (administering medication to oneself without medical supervision – sometimes without proper medical diagnosis)
- 3. **Consumption** – considerations when obtaining medicine. Medicine as a commodity. Accept or reject - The Web may provide more appealing affordances to procuring medicine than offline sources, or alternatively people are satisfied with obtaining their medicines from the traditional outlets.
  - 3.1. Convenience – anything that simplifies the process of obtaining medicine
    - 3.1.1. Cost (expense – cheaper)
    - 3.1.2. Quantity (bulk buying)

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- 3.1.3. Time (including the duration it takes to get the medicine such as speed of delivery and proximity to where the medicine is obtained from)
  - 3.1.4. Frequency (how often medicine is required)
  - 3.1.5. Discretion (provides the perception of anonymity)
  - 3.1.6. Ease (comfort and access when obtaining medicine)
  - 3.1.7. Choice (variety of products)
  - 3.1.8. Location (where the place to obtain medicines from is based)
- 3.2. Motivations – anything which provides people with a reason to act in a particular way e.g. obtain medicine from a certain place. Socially constructed perceptions of consumer behaviour influencing healthcare choices. Attitudes and beliefs which could inform the decision to use the Web to buy medicine.
- 3.2.1. Reputation (of the medicine the branding could suggest it is legitimate to use; or reputation of the place to obtain medicine)
  - 3.2.2. Jurisdiction (global differences in accessing medicine, needing health insurance, prescription costs)
  - 3.2.3. Advertising (marketing about medicine – may induce impulse purchases)
  - 3.2.4. Authenticity (products are genuine – satisfaction that medicine is real and the quality it should be )
  - 3.2.5. Availability (may be the only place to obtain certain medicine)
  - 3.2.6. Normalised behaviour (online shopping is normal consumer behaviour and medicine is just another commodity that people can purchase)

- 3.3. Justifications – reasons or explanations to defend actions or choices. The Web may allow people to overcome or fulfil issues.
  - 3.3.1. Need (sense of entitlement – they have to have the medicine)
  - 3.3.2. Desperation (due to the condition for which they want the medicine and its impact)
  - 3.3.3. Frustration (due to the circumstances surrounding trying to obtain medicine/treat a condition)
  - 3.3.4. Embarrassment (due to a particular condition)
  
- 4. **Risks** – Attitudes and beliefs towards safety and issues of harm, and concerns about obtaining and consuming medicine. Accept or reject – if people accept, and can overlook or disregard (disassociate themselves from the risk) such hazards they might use the Web to buy medicine – they are knowingly leaving themselves vulnerable. However, if they reject the risks, people may repudiate the potential of them occurring by keeping to the traditional route of obtaining medicine from a doctor or pharmacist.
  - 4.1. Health risks (issues that can cause potential risks to physical health)
    - 4.1.1. Fake medicine (including counterfeit medicine, substandard medicine and medicine which has knowingly been sold containing the wrong ingredients)
    - 4.1.2. Contamination (medicine has been stored incorrectly)
    - 4.1.3. Mislabelling (wrong labels have been mistakenly attached to medicine)
    - 4.1.4. Little or no information about side effects (knowledge about potential reactions, possible contraindications and the consequences of poly-drug use)

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- 4.1.5. Misuse of medicine (including addiction and overdose of medicine)
  
- 4.2. Security Risks (concerns about financial matters and loss of property)
  - 4.2.1. Fraud (including credit card fraud, identity theft, and not receiving items after paying for them – unscrupulous sellers)
  - 4.2.2. Organised crime (certain activities may be linked to or funding organised crime)
  - 4.2.3. Customs (items ordered in from another country may be intercepted and confiscated)
  - 4.2.4. PC viruses (clicking on links may make computers vulnerable to phishing attacks etc.)
  
- 4.3. Personal implications (of bypassing authorised channels of healthcare and obtaining medicine from the Web). Beliefs and attitudes about how you might be viewed based on your actions.
  - 4.3.1. Stigma (judgment from others, possibility of social exclusion or negative repercussion, linked with morality)
  - 4.3.2. Prosecution (threat of being in trouble with the legal authorities)

## Glossary

For the purposes of this research the following definitions apply. These are informed by the National Institute on Drug Abuse (NIDA) and the principles of prescribing as outlined by the British National Formulary (BNF), and the General Medical Council (GMC):

- Antipsychotics: Medicines used to treat some types of mental distress or disorder. They can also be used to help severe anxiety or depression.
- Benzodiazepines: A type of medicine known as tranquilisers, such as Valium and Xanax. They are some of the most commonly prescribed medicines in the US, and reportedly commonly abused.
- Drug: (Oxford English Dictionary definition) *“a medicine or other substance which has a physiological effect when ingested or otherwise introduced into the body or.....a substance taken for its narcotic or stimulant effects, often illegally”*.
- General Sale List (GSL): The medicines can be sold by any retailer, although they must still comply with general regulations regarding the sale and advertisement of medicines. They are also known as over-the-counter (OTC) medicines.
- Hallucinogens: These are a class of drugs that cause hallucinations — profound distortions in a person’s perceptions of reality. Hallucinogens can be found in some plants and mushrooms (or their extracts) or can be man-made, and they are commonly divided into two broad categories: classic hallucinogens (such as LSD) and dissociative drugs (such as PCP).
- Legal highs: Substances which produce the same or similar effects to drugs such as cocaine and ecstasy, but are not controlled under the Misuse of Drugs Act. It is, however, considered illegal under current medicines legislation to sell, supply or advertise them for “human consumption”. To get round this, sellers refer to them as research chemicals, plant food, bath crystals or pond cleaner.

## Glossary

- Licensed medicine: A medicine that has been assessed by regulators for, and meets acceptable standards of, efficacy, safety and quality; has been manufactured to appropriate quality standards; and when placed on the market is accompanied by appropriate product information and labelling.
- Lifestyle drugs/medicines: A term commonly applied to medicines which treat non-life threatening and non-painful conditions or those that are minor relative to others, such as erectile dysfunction, baldness, skin conditions or slimming.
- Medicine: (Oxford English Dictionary definition) *“the science or practice of the diagnosis, treatment, and prevention of disease or.....a drug or other preparation for the treatment or prevention of disease”*.
- Pharmacy-only medicines: These medicines are available only with advice and certain restrictions from a pharmacist, and can only be purchased through a registered pharmacy.
- Prescription-only medicines: Licensed products to which sales restrictions apply. These can only be safely used under the care and supervision of suitably qualified healthcare professionals, who can advise on potential side effects, interactions with other medicines and safe dosages. These products can only be legitimately sold by a registered pharmacy, on production of a prescription from an appropriate healthcare professional.
- Self-medication: (Oxford English Definition) *“administer medication to oneself without medical supervision”*.
- Stimulants: These increase alertness, attention and energy, as well as elevating blood pressure, heart rate and respiration. Stimulants are only used to treat a few health conditions, including ADHD, narcolepsy and occasionally depression.
- Unlicensed medicine: A product that has not been assessed for its quality, safety and efficacy by regulators – the risks of the product are unknown. Examples are counterfeit medicines and products making medicinal claims or containing medicinal ingredients without



appropriate authorisation. The term “unlicensed medicine” is used to describe medicines that are used outside the terms of their country’s licence or that have no licence for use in the country. Unlicensed medicines are commonly used in areas of medicine such as paediatrics, psychiatry and palliative care. They are also used, less frequently, in other areas of medicine.

- Withdrawn: A withdrawn medicine is one which has had its licence suspended by the regulator and consequently is no longer permitted to be supplied. The medicine has been assessed, the risks are known and the product no longer meets acceptable standards of efficacy, safety and quality.

Doctors with full registration who hold a licence to practise may prescribe all medicines, but not drugs in Schedule 1 of the Misuse of Drugs Regulations 2001. Those with provisional registrations and licences to practise may prescribe medicines in line with the supervisory conditions of their employment.

Medicines may be prescribed for use outside the terms of their licence, and unlicensed medicines may be prescribed as long as specific conditions are satisfied.



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## **Publications and Conference Items**

*Publications and Conference Items*

## **Publications**

Sugiura et al. *Novel psychoactive substances on the Web* (2014) White Paper

Sugiura, Lisa, (2013) *Public and private faces in web spaces – How Goffman’s work can be used to think about purchasing medicine online*. In the Working Papers on Health Sciences Journal. Aug, 2013.

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Sugiura, Lisa, Pope, Catherine, Weal, Mark, and Webber, Craig (2012) *Observing Deviancy Online*. In the proceedings of the Digital Research Conference 2012, Oxford

El-Din, Rasha. Salah and Sugiura Lisa (2013) *To deceive or not to deceive! Legal implications of phishing covert research*, Int. J. Intellectual Property Management, Vol. 6, No. 4

Sugiura, Lisa, Pope, Catherine and Webber, Craig (2012) *Buying unlicensed slimming drugs from the Web: a virtual ethnography*. In the proceedings of the Web Science Conference 2012, Chicago, US, 22 - 24 Jun 2012. 4pp

*Publications and Conference Items*



## Conference Presentations and Invited Talks

*Does the Web challenge our traditional ethical arrangements? 'The trials and tribulations of undertaking online observational research'* NCRM Research Methods Festival Session, Oxford, July 2014

*Is the purchase of prescription medicine from the Web a form of respectable deviancy?* The National Deviancy Conference, Teesside, June 2014

*Online presentations of health behaviours and digital interactions – how Goffman's work, can be utilised to understand the of buying of [prescription] medicine from the Web* The British Sociological Association Conference, Leeds, April 2014

Presented the initial findings of the Novel Psychoactive Substances on the Web project at the Royal Society, London, Feb 2014

*Online presentations: From deviancy to Goffman; how the Web endorses the unauthorised purchase of medicines* The European Society of Criminology Conference, Budapest, September 2013

*Public and private faces in web spaces: How Goffman's work can be used to think about the purchasing of prescription medicine online* The Health Sciences Postgraduate Research Conference, University of Southampton, June 2013

Selected to Represent the Digital Economy Funding stream at the RCUK Underpinning economic growth and wellbeing event, House of Commons, London, Dec. 2012

*Publications and Conference Items*

*Observing Deviancy Online* Digital Research Conference 2012, Oxford, Oct 2012

Digital Data, Digital Media and Healthcare to the Norwegian Centre for Telemedicine, Sept 2012

*Revisiting Deviancy with Web Phenomena* British Society of Criminology Conference 2012. Portsmouth, July 2012

*Buying Unlicensed Slimming Drugs from the Web: A virtual ethnography* Web Science 2012 Conference, Chicago, June 2012

EPSRC Digital Economy Review, Swindon, May 2012.

*What is Virtual Ethnography?* National Centre for Research Methods (NCRM) symposium on Qualitative Research, Jan 2012.

*Online accounts of consumer behaviour*, Tsinghua University, Nov 2011

