

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Medical profiling and online medicine: the ethics of 'personalised' medicine in a consumer age* between April 2009 and July 2009. The views expressed are solely those of the respondent(s) and not those of the Council.



July 2009

fpa response to Nuffield Council on Bioethics consultation on:
Medical profiling and online medicine: the ethics of 'personalised' healthcare in a consumer age

About fpa

fpa (Family Planning Association) is the UK's leading sexual health charity. Our mission is to help establish a society in which everyone has positive, informed and non-judgemental attitudes to sex and relationships; where everyone can make informed choices about sex and reproduction so that they can enjoy sexual health free from prejudice and harm.

fpa provides a comprehensive information service, including a national helpline which responds to over 50,000 enquiries a year on all aspects of sexual health. We produce a range of publications for professionals and the public on sexually transmitted infections, contraception and pregnancy choices, including abortion, and we distribute around 10 million pieces of literature a year. **fpa** provides a variety of resources, including training courses, for those involved in delivering sexual health services. We also run a series of community based sex and relationships education projects, both for young people and for parents. **fpa** provides a national voice on sexual health, working with professionals and the public to ensure that high quality information and services are available to all who need them.

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fpa welcomes the opportunity to comment on the Nuffield Council on Bioethics' consultation on the ethics of personalised healthcare in a consumer age. We have restricted the following comments to our areas of knowledge and expertise as an organisation which provides health information at a distance, including online.

Introduction

fpa provides objective and evidence based information on contraception, sexually transmitted infections, pregnancy choices, including abortion, and other aspects of sexual health directly to the public via our website, our telephone helpline and our web enquiry service, AskWES. The information booklets we produce are also used by health professionals when they are talking to service users. Our information is based on the latest available medical evidence and is reviewed by a group of healthcare professionals as well as being consumer tested.

fpa believes it is vital that people are able to access high quality, accurate information to enable them to maintain their sexual health and that of their partners. The development of technology such as the internet creates opportunities for providing this information to more people more easily. In addition, sexual health is something which people find it very difficult to talk about, which means that the internet can enable people to access some of the information they need without fear of embarrassment or stigma.

Medical products and services as consumer goods which people may choose to purchase

In principle, **fpa** supports widening access to health services and information. Within the area of sexual health there have been moves to widen access to products and services by making them available to purchase as well as continuing to provide them free of charge elsewhere. For example, emergency hormonal contraception can be purchased over the counter from pharmacies but it is also available free from general practice, contraceptive clinics, NHS walk-in centres and Accident and Emergency departments. While we welcome the efforts to widen access to emergency hormonal contraception by making it available to purchase, we believe it is important that people are made aware that it is also possible to access it free of charge, including when it is advertised and where it is sold. There is a risk that, if people are not aware that they can access a service free of charge, they will be deterred from seeking the advice, care and treatment they need because of concerns about paying for it.

It is also important that, where people do choose to buy products, they receive sufficient information about how to use the product, what to do if they have a problem after taking it and also what follow up might be necessary. Some

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callers to **fpa**'s helpline who have purchased products are subsequently embarrassed, uncomfortable or uncertain about seeking help or advice from NHS services if they have a problem because they have purchased something from outside the NHS.

Electronic health records

While it can be useful for people to be able to access their health records online, it is vital that there are sufficient safeguards in place to ensure that the information is stored confidentially. When people access sexual health services they are often particularly concerned about the confidentiality and how information about them will be shared and used. Information which people store on online health records must not be shared without their consent. There should be clear safeguards in place to ensure the information cannot be accessed by anyone but those people chosen by the service user.

Using online sources for diagnostic purposes

As has been noted above, **fpa** believes it is vital that people are able to access information to enable them to maintain their health and wellbeing and the internet can provide people with easier access to information to do this. In principle, we would support people using online diagnostic tools as long as the tools make it very clear for service users how to interpret the results and what to do next, including how to access services. In many cases, it is helpful for people to receive test results from a professional who is able to interpret them reliably, and online tools may not always be able to achieve this.

Purchasing prescription medicines over the internet

fpa is aware that some people do try to buy medicines online, including prescription only medicines although calls to our helpline suggest that there is still a tendency for people to want to have contact with a healthcare professional when buying over the internet. In many cases, people have concerns about how they would know a site was safe and how it is possible to assess the safety of medicines when they are bought online. In addition, some people are reluctant to pay for medicines or products which they are aware they can access free of charge elsewhere, for example emergency hormonal contraception or pregnancy testing kits. The availability of medicines, including prescription medicines online, can add to people's confusion about what they have to pay for and what they can access free of charge.

Where people do buy prescription medicines online it is obviously important that they use a registered site and while the Royal Pharmaceutical Society of Great Britain's logo scheme may well go some way to helping people to identify registered sites, using the logo is not compulsory. The issues around buying

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prescription-only medicines online without a prescription are much wider, as this is illegal, and much more likely to lead to significant problems such as not receiving the correct medication or receiving something which would be harmful.

Advertising prescription medicines directly to consumers

fpa has concerns about allowing advertising of prescription medicines directly to consumers. In the vast majority of cases it is important that people seek advice from a qualified medical professional and in particular know when and how to access further advice if their symptoms do not improve. For example, many women buy and use Canesten without seeking medical advice. This is not a problem if they have thrush and seek further advice if their symptoms continue. However, many women repeatedly use Canesten without considering that there may be another underlying condition which is causing the symptoms. Advertising prescription medicines directly to consumers may increase issues like this as people diagnose themselves and then ask their doctors for particular treatments.

Remote access to GP services through telemedicine for remote and rural areas

fpa welcomes the provision of GP services through telemedicine where this increases access to reliable information and advice in remote and rural areas. We understand that some obstetric care is delivered in a similar way in areas such as the Hebrides and this can be reassuring and convenient for women. It is important, however, that telemedicine is only used for delivering GP services where there are genuine issues with rurality and remoteness and not simply as a means of reducing GP services.