

## **Developing Patient Reported Experience Measures (PREMs) for sexual health: a proposed approach**

### **Introduction**

The Advisory Group on Contraception (AGC) is made up of leading clinicians and advocacy groups who have come together to discuss and make policy recommendations concerning the sexual health and contraceptive needs of women. The membership of the AGC is included in Annex 1.

The AGC welcomes the Department of Health's commitment in the White Paper, *Healthy lives, healthy people: Our strategy for public health in England* to adopt a life stage approach to public health, accepting that people will require different support at different points. This approach should underpin the update to sexual health policy.

Although outcomes for contraception can be measured relatively easily for teenagers (through the teenage conception rate) it is more problematic to do so for older women. For example:

- Data on 'unwanted' pregnancies is difficult to collect, since an unintended pregnancy is not necessarily unwelcome
- There are potential perverse consequences for using abortion or repeat abortion rates as a proxy for an outcome (it could, for example, incentivise commissioners to reduce access or take steps to deter women from seeking an abortion)
- There is not yet a consensus on appropriate Patient Reported Outcome Measures for contraception

However, the AGC does not believe that these are insurmountable challenges. As an interim step, the AGC suggests that Patient Reported Experience Measures (PREMs) of how supported service users aged 20+ feel in managing their sexual and reproductive health should be used as a proxy for contraceptive outcomes.

A PREM for contraception could build on the experience in other areas of care, such as cancer. It should be noted that many contraception providers are already required to collect such information for service users but that this information is not collated, published, or used to measure outcomes. This paper sets out how PREMs could be used to measure outcomes in contraception to ensure service users' needs are being met.

### **The role of patient experience in measuring outcomes**

Patient experience is recognised as an outcome in itself, forming Domain 4 of the NHS Outcomes Framework. Patient experience can be measured in a variety of different ways:

- Generic surveys of user satisfaction
- Tailored condition or service-specific surveys of user experience
- Patient reported experiential feedback
- Patient reported outcomes, focusing on functional changes

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The Department of Health and NHS already have good experience of conducting large-scale patient experience research, including:

- GP Patient Survey<sup>1</sup>
- Inpatient Services Survey<sup>2</sup>
- National Patient Choice Survey<sup>3</sup>
- National PROMs programme<sup>4</sup>
- Cancer Patient Experience survey<sup>5</sup>
- Personal Social Services Survey of Adult Carers<sup>6</sup>

In addition, the NHS is already using patient experience as a 'live' performance measure, including incorporating it into financial incentives. For example, in 2010/11 109 CQUIN schemes were introduced which directly incentivised improvements in patient experience<sup>7</sup>. Many service providers are already required to collect information on patient experience as part of their standard contractual arrangements.

### **The value of PREMs for contraception and sexual health**

Effective contraception and sexual health services require patient concordance with the method of choice. Such services are usually used by 'healthy' people who therefore have little incentive to comply with a protocol which is delivering a poor experience. Therefore promoting a positive experience of a service can play an important role in improving outcomes beyond patient experience itself.

Contraception and sexual health services are extremely diverse, encompassing a wide range of providers operating in different settings and offering different forms of intervention. It is therefore critical that this multiplicity of providers can be compared by users, in a meaningful and informed manner. In short, accurate information on patient experience is vital to making the market work in contraception and sexual health.

### **Other uses for patient experience measures**

In addition to enabling the Department of Health, Public Health England and the NHS Commissioning Board to track improvements in outcomes, data on patient experience can have a number of uses, including:

<sup>1</sup> Department of Health, *GP Patient Survey, January to December 2010*. 17 March 2011. Available at: <http://www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/GPpatientsurvey2007/index.htm>

<sup>2</sup> Care Quality Commission, *Inpatient Services Survey 2010. April 2011*. Available at: <http://www.cqc.org.uk/aboutcqc/howwedoit/involvingpeoplewhouseservices/patientsurveys/inpatientservices.cfm>

<sup>3</sup> Department of Health, *National Patient Choice Survey – February 2010, England*. 30 June 2010. Available at: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH\\_116958](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_116958)

<sup>4</sup> NHS Information Centre, *Provisional Monthly Patient Reported Outcome Measures (PROMs) in England – April 2009 to November 2010. Pre and post-operative data: Experimental Statistics*. 14 April 2011. Available at: <http://www.ic.nhs.uk/statistics-and-data-collections/hospital-care/patient-reported-outcome-measures-proms>

<sup>5</sup> Department of Health, *National Cancer Patient Experience Survey Programme – 2010*. 10 December 2010. Available at: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH\\_122516](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_122516)

<sup>6</sup> NHS Information Centre, *Personal Social Services Survey of Adult Carers in England – 2009/10*. 30 June 2010. Available at: <http://www.ic.nhs.uk/pubs/psscscarersurvey0910>

<sup>7</sup> MHP Health Mandate, *Accounting for Quality: an analysis of the impact of quality accounts in the NHS*. September 2010.

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- Supporting commissioners in exercising oversight of services
- Enabling services providers to identify areas where improvements are required
- Assisting women in making choices about where to receive contraception support and what method would be most appropriate for them

An example of where patient experience data are being used to improve outcomes is in the field of cancer. The National Cancer Patient Experience Survey was conducted and published in 2010 and incorporated detailed feedback from 69,000 patients across a range of different forms of cancer and parts of the patient pathway. The findings from the Survey are now being used to:

- Inform progress on Domain 4 of the NHS Outcomes Framework
- Support commissioners in incentivising improvements in patient experience of cancer services (a CQUIN indicator is being developed)
- Engage with providers to secure improvements in quality, with a targeted programme of engagement underway with low performing trusts
- Enable charities to support patients in making choices which reflect their lifestyle and preferences, with a detailed dataset providing tumour- and trust-specific data being made publicly available
- Provide a platform for further research, with the dataset being used to identify trends in service delivery and outcomes

The [National Cancer Patient Experience Survey report](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_122516) can be read here:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH\\_122516](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_122516)

The [detailed provider level analysis](http://www.quality-health.co.uk/cancer-reports) is available here: <http://www.quality-health.co.uk/cancer-reports>

### **Developing PREMs for contraception and sexual health**

If the Department of Health wished to develop PREMs for contraception and sexual health, a number of steps would be necessary. These include:

1. Map the areas on the pathway where it would be useful to survey patients
2. Develop a draft of questions for service users
3. Test the questions for usability and sensitivity
4. Identify a mechanism for conducting and analysing the survey

The AGC would be happy to participate in detailed work to develop appropriate, usable PREMs. The following officials in the Department of Health may be helpful in advising on patient experience surveys:

- Rachel Reeves, Patient Experience and User Satisfaction team
- Tim Elliott, who led the development of the National Cancer Patient Experience Survey

The following external organisations may also be able to assist:

- Penny Woods, Chief Executive, Picker Institute Europe
- Dr Reg Race, Managing Director, Quality Health

*Advisory Group on Contraception, 5 May 2011*

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## **Annex 1 – membership of the Advisory Group on Contraception**

The members of the AGC are:

**Dr Anne Connolly**, General Practitioner, The Ridge Medical Practice and Clinical Lead for Women's and Sexual Health, NHS Bradford and Airedale

**Ann Furedi**, Chief Executive, bpas

**Baroness Gould of Potternewton**, Chair of All Party Parliamentary Group on Sexual and Reproductive Health in the UK, and Co-Chair of the Sexual Health Forum

**Dr Kate Guthrie**, Consultant Gynaecologist, Hull Community Healthcare Partnership

**Natika Halil**, Director of Information, FPA

**Ruth Lowbury**, Chief Executive, Medical Foundation for AIDS and Sexual Health (MedFASH)

**Tracy McNeill**, International Vice-President and Director of UK and West Europe, Marie Stopes International

**Jennifer Owen**, Senior Commissioning Manager, NHS Halton and St Helens

**Jill Shawe**, National Association of Nurses for Contraception and Sexual Health

**Dr Connie Smith**, Central London Community Healthcare NHS Trust

**Dr Anne Szarewski**, Clinical Consultant, Honorary Senior Lecturer, Centre for Cancer Prevention, Wolfson Institute of Preventive Medicine and Associate Specialist, Margaret Pyke Centre

**Dr Chris Wilkinson**, Lead Consultant, Margaret Pyke Centre

### **Contacting the AGC**

The secretariat for the AGC is provided by MHP Communications. Should you wish to contact the AGC please email [contraception@mhpc.com](mailto:contraception@mhpc.com) or telephone MHP on 020 3128 8106.

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