



Public Health
England

Protecting and improving the nation's health

What do women say?

Reproductive health is a public health issue

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Executive summary

The document presents the findings from a survey of more than 7,500 women and focus group discussions to find out how women experience reproductive health issues and some of the choices they make.

The reproductive lifecourse from menarche, through to menopause and beyond is a normal and universal process. The relative importance of reproductive issues vary between individuals and also at different stages of life. Many women have difficulties that impact on their wellbeing. These impacts are often overlooked by both women themselves and those around them. Reproductive experiences and choices for women are embedded in and influenced by societal constructs. There is an expectation about what is normal and how reproductive choices should be enacted. There is a need for reproductive health to be normalised allowing frank and open discussion, and enabling those who need additional support to reach it.

Knowledge of their reproductive health was seen as a key factor in women being able to both manage unwanted symptoms and having a voice in making positive reproductive choices. Women of all ages cited school as the place where they had gained most of their knowledge but that information they had received had often been basic and out of touch with their lived experience. They frequently remained unaware of what to expect or how to manage their reproductive health needs throughout their lives.

Much of the discourse about reproductive health centres around achieving or preventing pregnancy. Women described the conflicts that they experienced between their own personal preferences about having children, relationships, career and financial pressures against broader societal expectations of whether and when pregnancy is expected to happen. In particular there was a perception that not having children or having them later was negatively viewed. Women who did see having children as part of their plan, assumed that this would be easily achievable which left women who did experience difficulties in conceiving feeling bewildered.

For most women, preventing pregnancy was the most important reproductive issue throughout most of their lives. This priority was most marked for younger women who were also most likely to use the least reliable contraceptive methods such as pills and condoms. Older women tended to use more effective methods such as the intrauterine

device (IUD). One in 4 women who used condoms for contraception admitted that they did not use them regularly, significantly increasing their risk of unintended pregnancy.

In general, women reported that General Practice (GP) was their preferred place to obtain their contraception including for the implant or IUD, although a significant minority preferred a sexual health setting. Women under 35 were more likely to receive their IUD in sexual health clinics compared with women over 35 receiving them in GP clinics. A total of 80% of women using pills received them from the GP although more than half would prefer to receive them elsewhere such as in pharmacy or online.

Symptoms associated with the reproductive health also had an important impact on women's wellbeing. A total of 80% of women in our survey described experiencing unwanted reproductive health symptoms such as heavy menstrual bleeding, severe menopausal symptoms or postnatal symptoms. Menstrual problems were particularly common in women under 25. More than 80% of women experienced difficulties postnatally, this was more common in women under 25. More than one in 3 women in this age group reported experiencing postnatal depression. Women experiencing symptoms were often reluctant to share their experiences for fear of being judged. These feelings were reinforced in different ways including at work, school and within healthcare settings.

Only around half of women with symptoms sought help for them, and less than a third of those with postnatal symptoms. Women under 25 in the postnatal period were least likely to seek help in spite of being most likely to experience symptoms. Care-seeking was not necessarily related to the perceived severity of symptoms. Embarrassment, fear of being judged and the stigma that surrounds reproductive health issues were all important barriers to seeking care. For those who did seek healthcare, good communication and rapport that enabled honest and open dialogue was essential to this being satisfactory, particularly in relation to issues that might be difficult or embarrassing to discuss.

Over all this study has highlighted that women desire that reproductive health issues are normalised and destigmatised so that they can be discussed openly and self-managed where possible. Where care is needed, information is needed to know when and how to seek appropriate care with confidence that this would be managed and communicated effectively.

Acknowledgements

This report and the accompanying documents have been the effort of a large team of contributors. In particular we would like to thank Carla Stanke for her work in designing and conducting the online survey and focus group discussions. We would also like to thank all the women who completed the survey or participated in the focus groups.

Background

Introduction

The World Health Organisation (WHO) defines reproductive health as a “state of physical, mental, and social well-being in all matters relating to the reproductive system. It addresses the reproductive processes, functions and system at all stages of life and implies that people are able to have a satisfying and safe sex life, and that they have the capability to reproduce and the freedom to decide if, when, and how often to do so.” (1)

Reproductive health is a public health issue with far reaching impacts, especially for women, throughout the whole of life, with intergenerational effects on children and families, and economic impacts through lost hours of work and school absenteeism as a result of unwanted reproductive symptoms(2). Stigma, embarrassment and taboos all surround reproductive issues making it difficult to talk about them (3, 4). The National Survey of Sexual Attitudes and Lifestyles (NATSAL) found that 10% of women have experienced non-volitional sex but often do not tell anyone; more than one third of women did not plan to have or were ambivalent about their pregnancies that continued to term and are therefore more likely to result in complications (5, 6); It is often difficult for women to reach information or care that they need because of these and many other barriers.

Little is known about how women in the UK perceive their reproductive health and what factors influence the choices they make in relation to their reproductive health. Approaches that address the social determinants of reproductive health, encouraging and supporting women in managing debilitating physiological symptoms and addressing universal access from a population perspective, is lacking. Enhancing and reframing the narrative around reproductive wellbeing is needed to understand what success looks like in terms of population level choice, control and empowerment. Learning from women about their concept of good reproductive health is the first step in doing this.

Aim

To gain a better understanding of women's experiences of and preferences for reproductive health and healthcare in order to inform the development of a PHE Reproductive Health Strategic Action Plan.

Objectives

- Deliver an online survey to women aged 16 and over living in England
- Run a series of 5 focus group discussions in 5 different cities in England, exploring women's experiences of reproductive health, how they make choices and how health care services support these choices
- Understand women's needs for services
- Describe patterns of and preferences for service use

Purpose of this document

What do women say? is an analysis of women's experiences of reproductive health and healthcare. It is part of a suite of 3 documents entitled 'Reproductive health is a public health issue'. The other 2 documents are:

- "What does the data tell us?" a baseline assessment of the reproductive health of the population through data.
- 'A consensus statement' a set of shared values and on which to base future models of care that works for the user across the whole reproductive life-course

Together these will form the basis of PHE strategy for improving reproductive health of the population.

The documents are intended to:

- Introduce reproductive health as a public health issue
- Inform local prioritisation and planning
- Provide a baseline for the upcoming reproductive health action plan

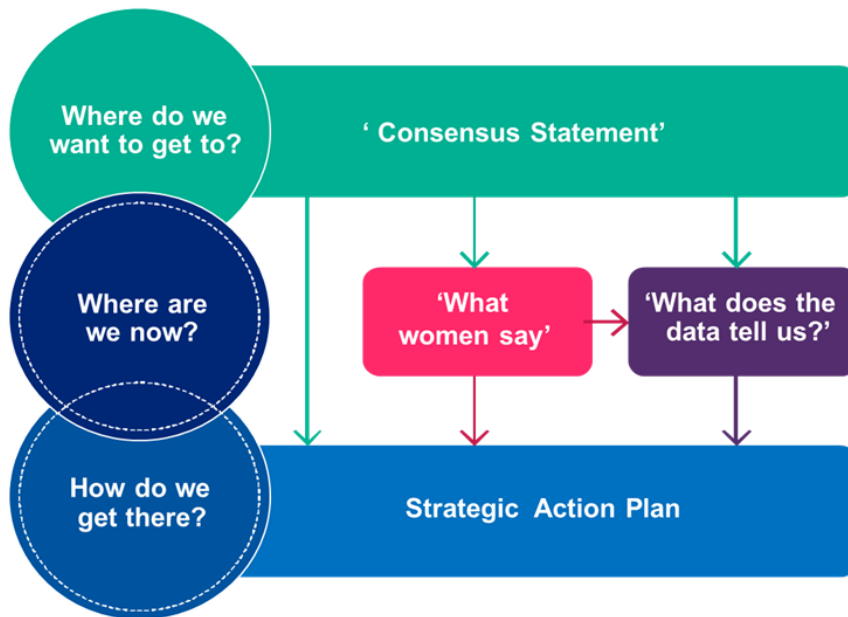


Figure 1: A diagram to illustrate how the suite of documents ‘Reproductive health is a public health issue’ will feed into the development of the reproductive health action plan due to be published in 2019

Methods

Focus Groups

Five focus groups in 5 different cities (London, Leeds, Bristol, Nottingham, and Newcastle), with 10 to 12 participants per group. Participants will be sampled from the People’s Panel in the first instance. Participants were sampled across different age groups and across a range of ethnicities and socio-economic backgrounds. They were asked about their reproductive health and illness across the life-course including menstruation, contraception, pregnancy, menopause and reproductive health morbidities and their experiences of reproductive healthcare. The discussions were intentionally broad and participant-led to ensure that the issues that were important to the women themselves were captured. The discussions were recorded and analysed using deductive and inductive qualitative analyses.

Online Survey

Following this an anonymous online self-completion survey was conducted for women aged 16 years and older living in England. Survey questions included validated questions where possible and topics were shaped by the issues that had been raised through the focus groups. A descriptive analysis was conducted describing the characteristics of the survey respondents and key outcomes including patterns of service use and preferences. Univariate and multivariate regression analyses were

carried out to examine associations between selected characteristics and key outcomes.

Findings from survey and focus groups

A total of 48 women participated in the focus groups: 27 were aged 18 to 39 and 21 were aged 40 and older.

There were 7,367 responses to the online survey. The demographics of the study population relative to the England population are presented in Figure 2. Women aged 25 to 34 (34% of the sample compared with 17% of England population), and those aged 35 to 44 (26% compared with 16% of England population) were over-sampled. Age-standardisation was included in the analysis to account for this difference.

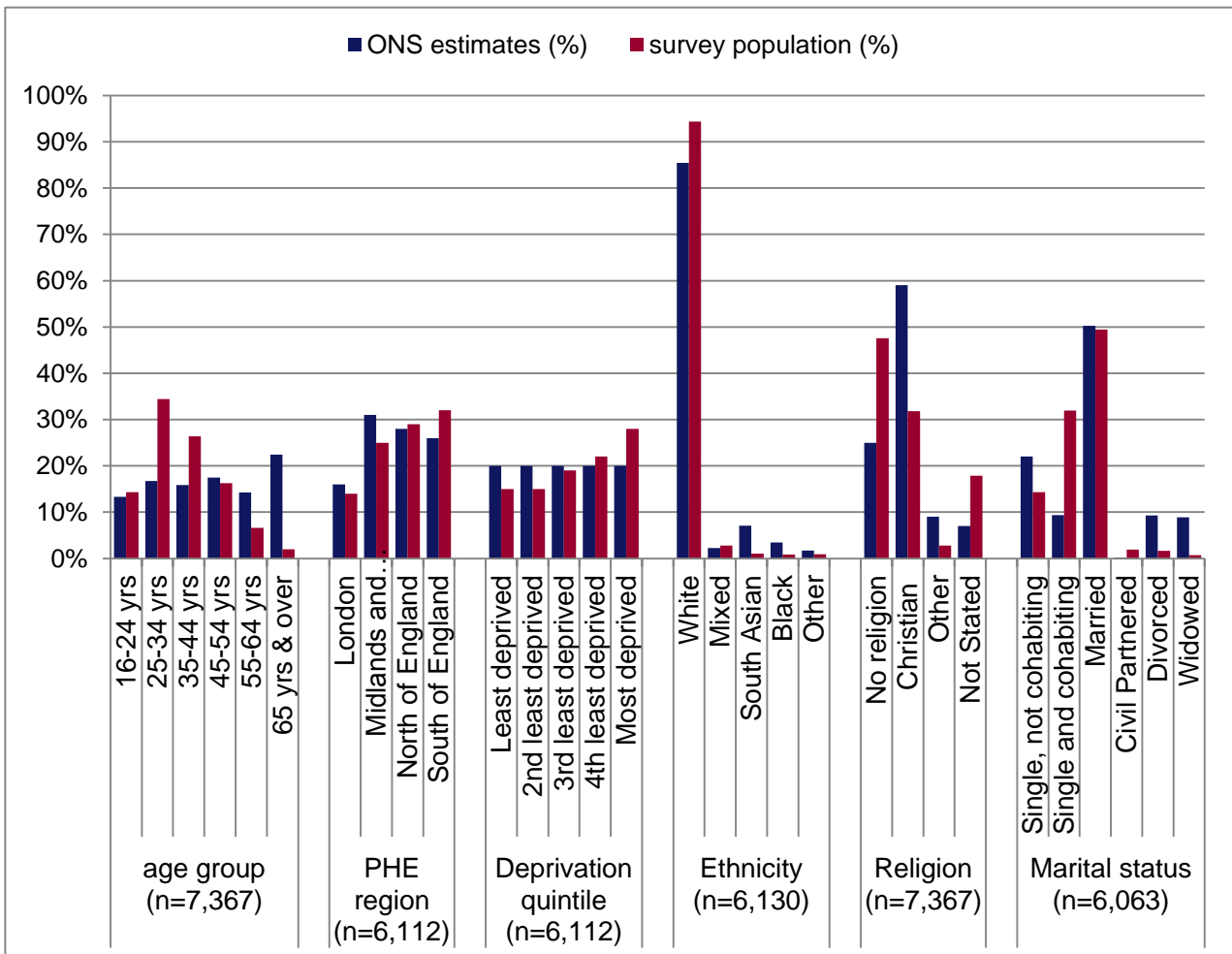


Figure 2: Proportion of survey responders compared to general female population, by age group, PHE region, deprivation quintile, ethnicity, religion and marital status, England 2017

Women’s Reproductive Health Priorities

Survey participants identified that their greatest reproductive concerns were to not get pregnant (particularly younger women), to have an enjoyable sex life, to manage reproductive health symptoms and to attend screenings for early identification of adverse reproductive conditions. Different issues took on relatively greater or lesser importance at different stages of life (Figure 3).

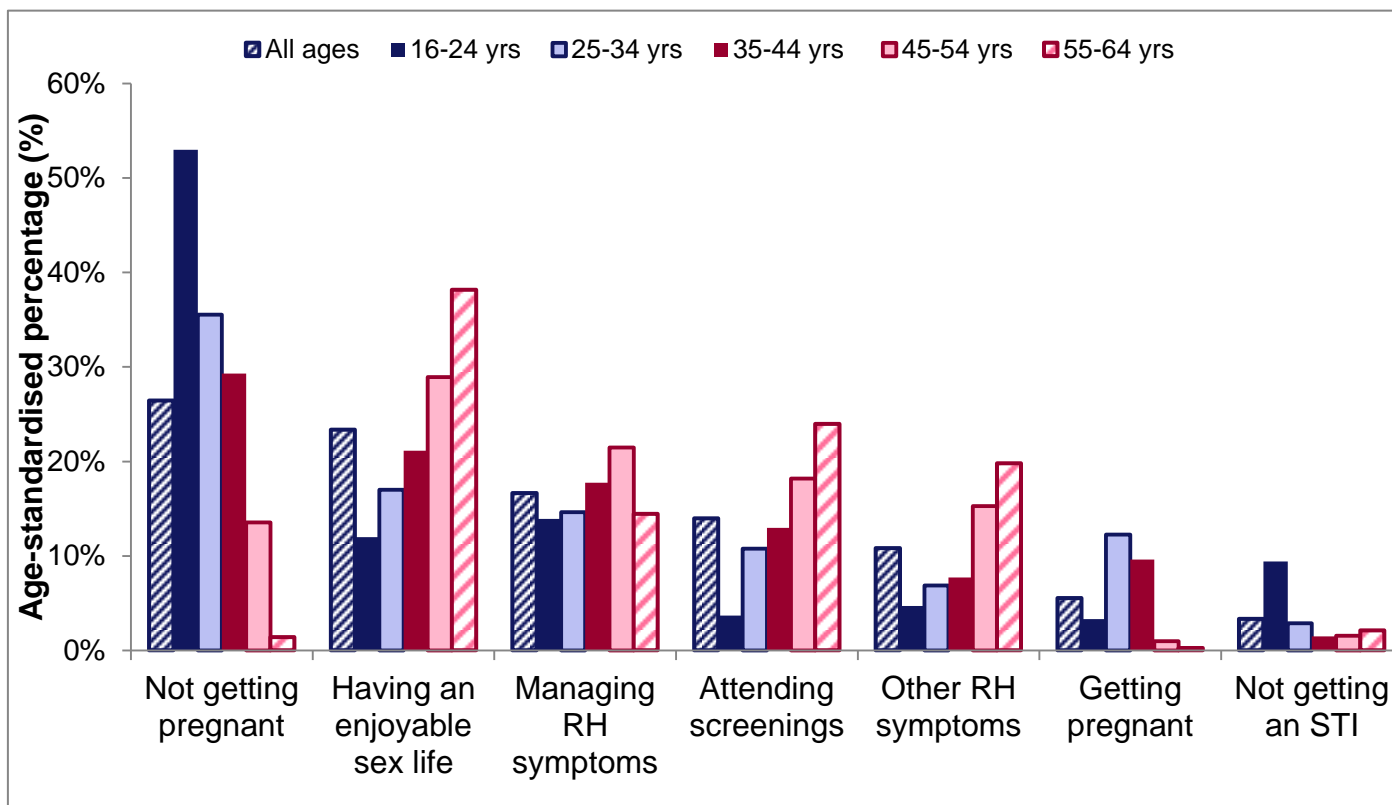


Figure 3: Most important reproductive health issue, by age group (n=6,744, weighted %)

The focus group discussions, gave wider insights into the ways in which womens’ lives were affected by these reproductive issues including painful and heavy periods; unwanted contraceptive side effects; struggles with infertility; post-natal depression; unwanted menopausal symptoms and reproductive health morbidities.

“...I look back and I think how much of my life I’ve lost to my periods...It’s only when you step back and think other women don’t go through this every month...”

“...it’s been an atrocious, ferocious and frightful experience (menopause)...”

Shame, embarrassment or discomfort in relation to reproductive health were often felt and experienced in many different ways. This could influence how manageable symptoms were and, whether or not care was sought. Socio-cultural expectation,

responses of healthcare professionals and perceptions at home, work and at school were all important in influencing this experience.

Women saw it as important to take control of their own “reproductive journeys” and to have a voice in decisions influencing their reproductive health. They were more able and empowered to do this if they felt they had a better understanding of their bodies and the ways in which they worked, for example when their periods started, in relation to the choices of contraception and diligence in its use or managing menopausal symptoms when they occurred.

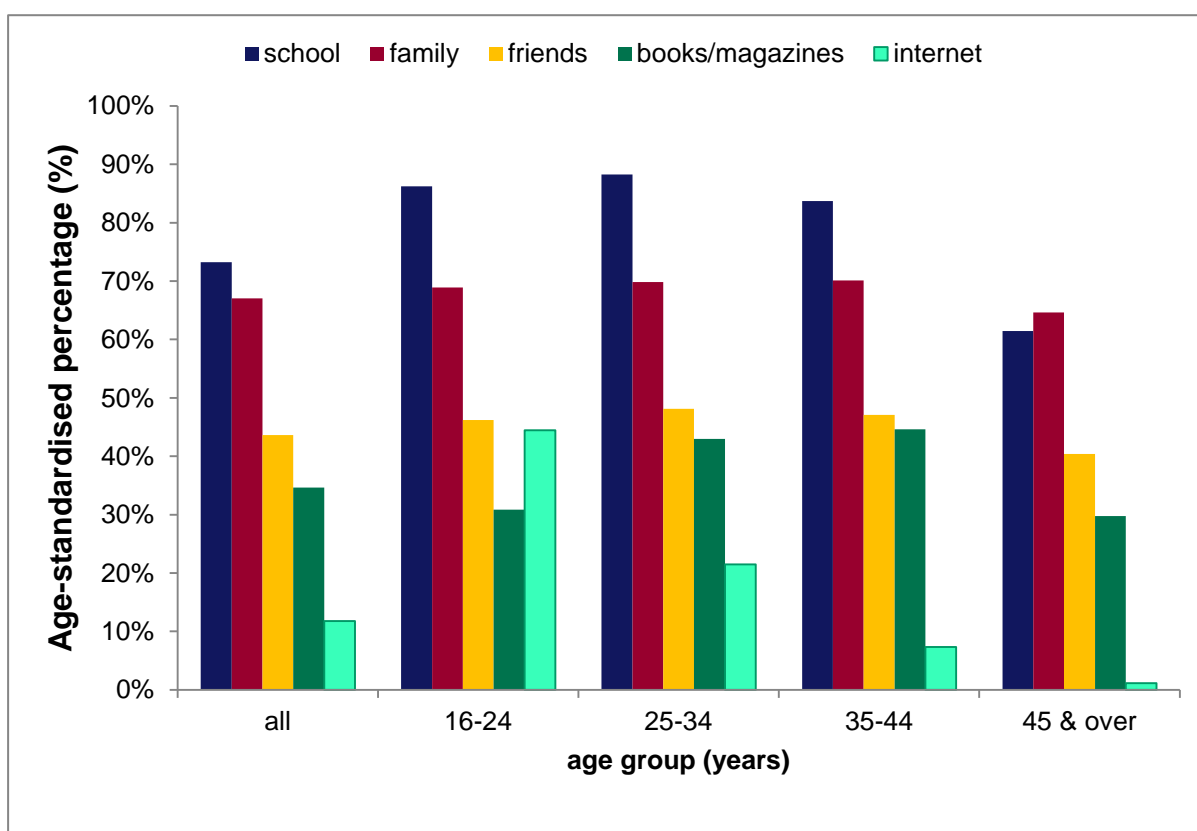


Figure 4: Proportion of women by source of knowledge on fertility, by age group

Women recognised that not all information sources were of equal quality and those with NHS branding were often seen as trustworthy. Women received information from many different sources including significant others (family—usually mothers and sisters, friends and partner), school, the internet, magazines and books, leaflets from GP surgeries and online groups (Figure 4). Three quarters of women had learned most of their information from school and little since then. The internet was often a source of ongoing information particularly for younger compared with older women.

Information received through traditional channels such as school was often described as basic “scientific” and bore little relationship to lived experience. Women of all ages described wanting more practical information such as being able to understand what

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constitutes 'normal' reproductive health and whether their own experiences fall within this spectrum, as well as a general understanding on how to manage when they experienced difficulties.

A lack of knowledge was often felt to be the cause of actual or anticipated poor experiences

“...she (my mother) gave me a pad and I didn’t know what to do with it. I thought...that the sticky side went up.”

“...I know every woman goes through the menopause but I actually don’t know what’s going to happen to me...I have no idea.”

“If I had had the right information about how to live with menopause, with the symptoms, maybe could have changed something but now, I don’t recognise my body anymore.”

Enacting reproductive choices

There were a range of factors operating that influenced women’s reproductive choices and ability to enact them. These included medical factors, career goals, culture, service availability and the perception of external pressures and assumptions. Much of reproductive life was felt to be spent avoiding pregnancy with an underlying assumption that pregnancy, if desired, would be straightforward to achieve.

“You spend years not trying to get pregnant, and then when you’re trying to get pregnant, you think it’s just going to happen.”

Later child rearing was increasingly seen as a norm.

“You go to primary schools, you see a lot of the parents are quite older...you know it’s (because of) career choices...”

Although women recognised that it was a challenge to navigate a perceived ‘proper’ sequence of life events within a context of competing pressures such as education, career, finances and relationships. Women felt that societal, social and personal expectations made it more difficult to make individual choices freely and seek appropriate care. For example, women could feel judged when seeking care if they believed that they could be seen to have made a poor reproductive choices (such as obtaining emergency contraception or information about abortion or sexually transmitted infections). Equally they might feel embarrassed that they had failed to fulfil a proscribed female role.

“If you can’t carry a child, you’re not a mum, you’re not a woman.”

Later child rearing was felt to be seen as negative particularly from healthcare provider perspectives.

My GP just said, ‘well you should have had your children earlier...you’re going to find it very difficult now. You’re just about to hit 30. The optimal time is about 22.’ ”

Despite these challenges, most women agreed that not getting pregnant was the overriding priority throughout most of the reproductive lifecourse.

“... I never thought about having children at all. I just thought about not having children.”

“...I swore I would never ever ever ever get pregnant again and I would never ever ever have a baby again so I used every contraception known to man, woman and child in this country...”

This was a particularly priority for women having heterosexual relationships who never planned to have children. However it could be difficult to be honest and open about this choice

“...I never had the urge for a child and it’s hard to say that.”

Use of contraception

Most women (75%) that need contraception (having heterosexual relationships and not wanting to be pregnant), across all age groups, were using at least one method, and 68% were using their method regularly. The highest proportion of contraception users were among women aged 16 to 24 years. Regularity of use of contraception declined with age (Figure 5).

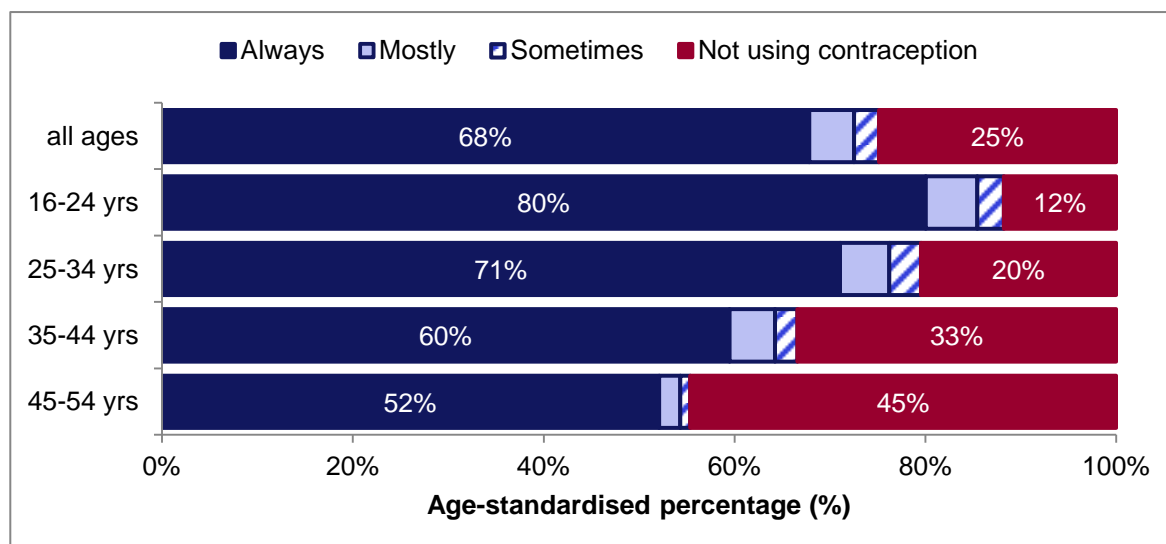


Figure 5: Regularity of use of contraception among women at risk of unplanned pregnancy, by age group, England 2017 (n=3,083)

Around one third of women currently using contraception reported use of a long-acting method such as an IUD or implant and one third were using a pill. The proportion of women who used IUD increased with age, whereas the proportion of women who used the implant or pill/patch decreased (Figure 6).

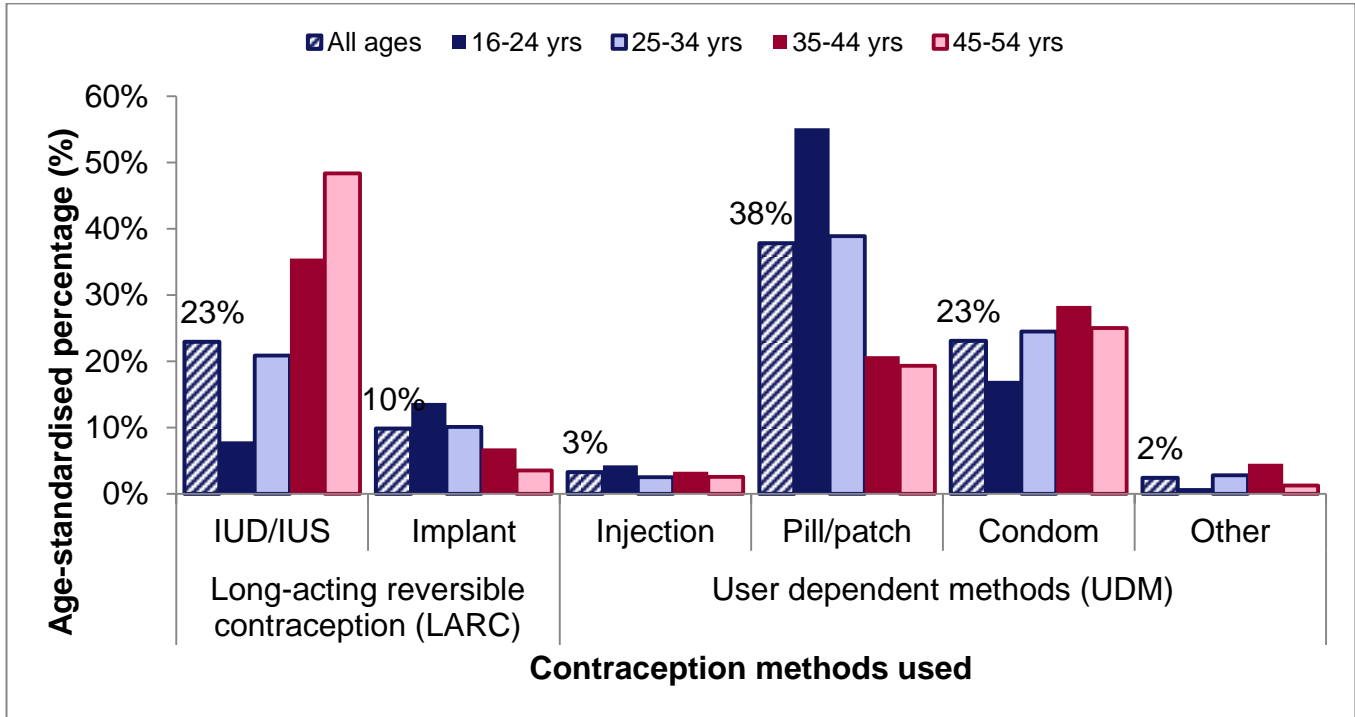


Figure 6: Most effective contraceptive method* used among women at risk of unplanned pregnancy who were using contraception, by age group England 2017 (n=2,326)

*When a woman had more than one contraceptive method, the most effective contraceptive method was presented in the figure.

Of women who used user-dependant rather than longer acting methods, more than 95% of women using pills and the injection reported “always use” whilst one in 4 women using condoms for contraception did not use them regularly (Figure 7).

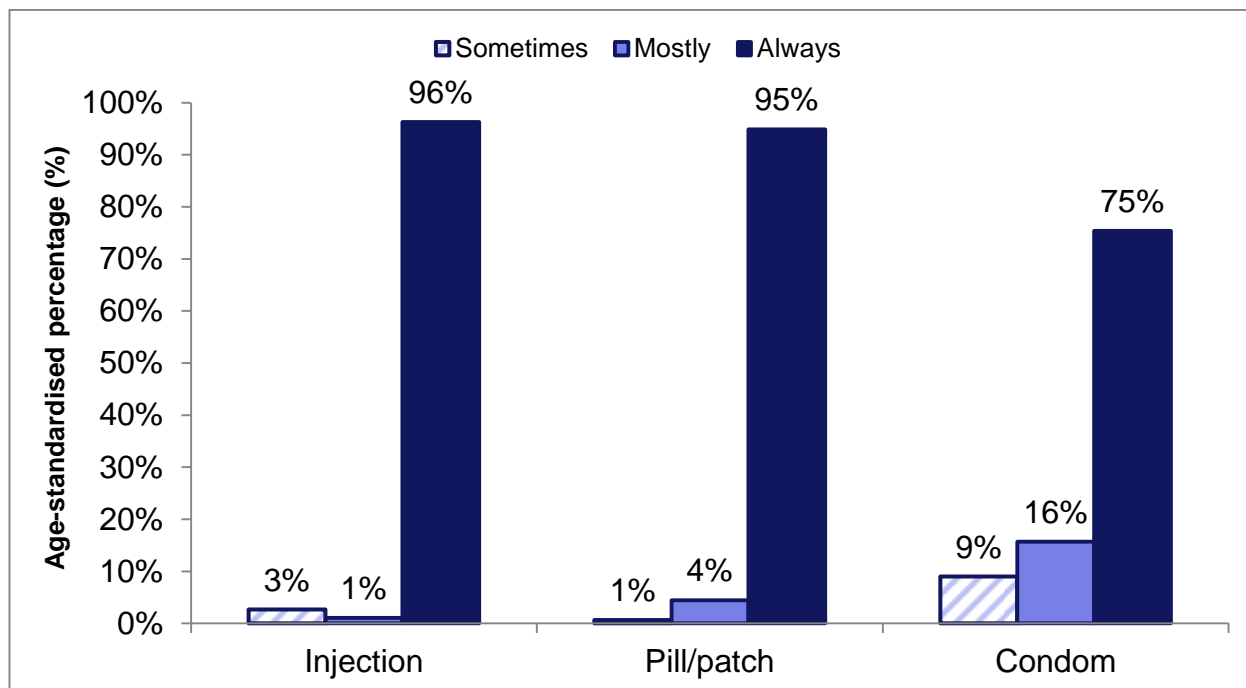


Figure 7: Most effective user dependent contraceptive method* used by regularity of contraception use among women at risk of unplanned pregnancy, England 2017

Preference for IUD use was highest in women aged 34 to 44 (38%). Half of women using the IUD received it from their GP or Practice nurse (51%), and 41% from a Sexual Health Clinic (SHC). SHC's were the most common source for younger women whilst GP's were the most common source for older women. Women using the GP were generally the most satisfied with their place of care (Figure 8).

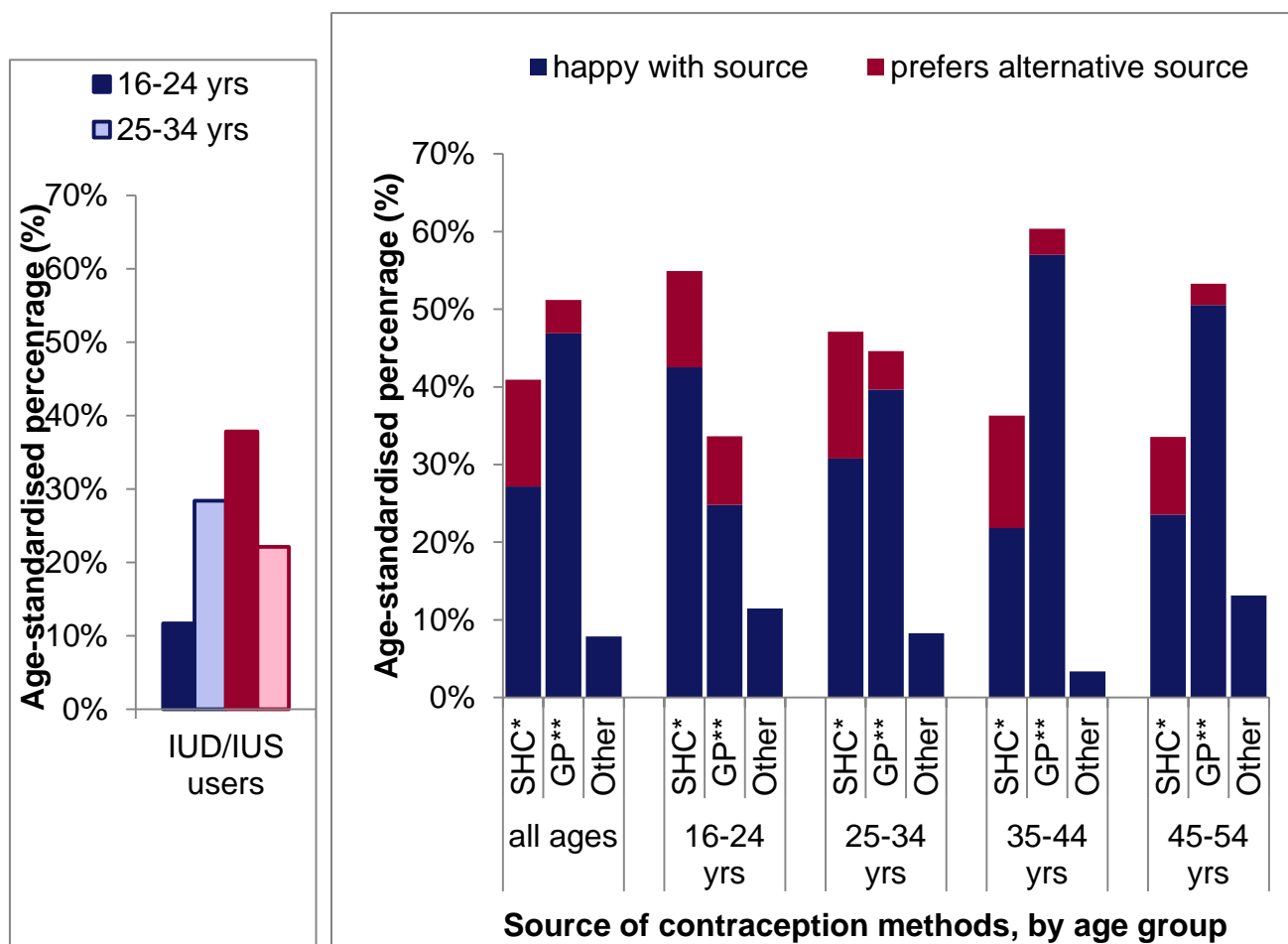


Figure 8: Proportion of women at risk for unplanned pregnancy who were using IUD/IUS who were satisfied or preferred alternative source of IUD/IUS, by age group, England, 2017 (n=496)

SHC* refers to Sexual Health Clinic which includes GUM clinic, family planning clinic, contraceptive clinic, reproductive health clinic. GP** refers to general practitioner or practice nurse from your general practice.

Overall age distribution of IUS/IUD users will not correspond to Figure 9 where proportion of different methods add up to 100%.

Preference for implant use was highest in women aged 16 to 24 (45%). Over half of women using the implant received it from their GP or Practice nurse (53%), Women in the 25 to 34 year old age group were the only group more likely to get their implant from SHC'ss (Figure 9).

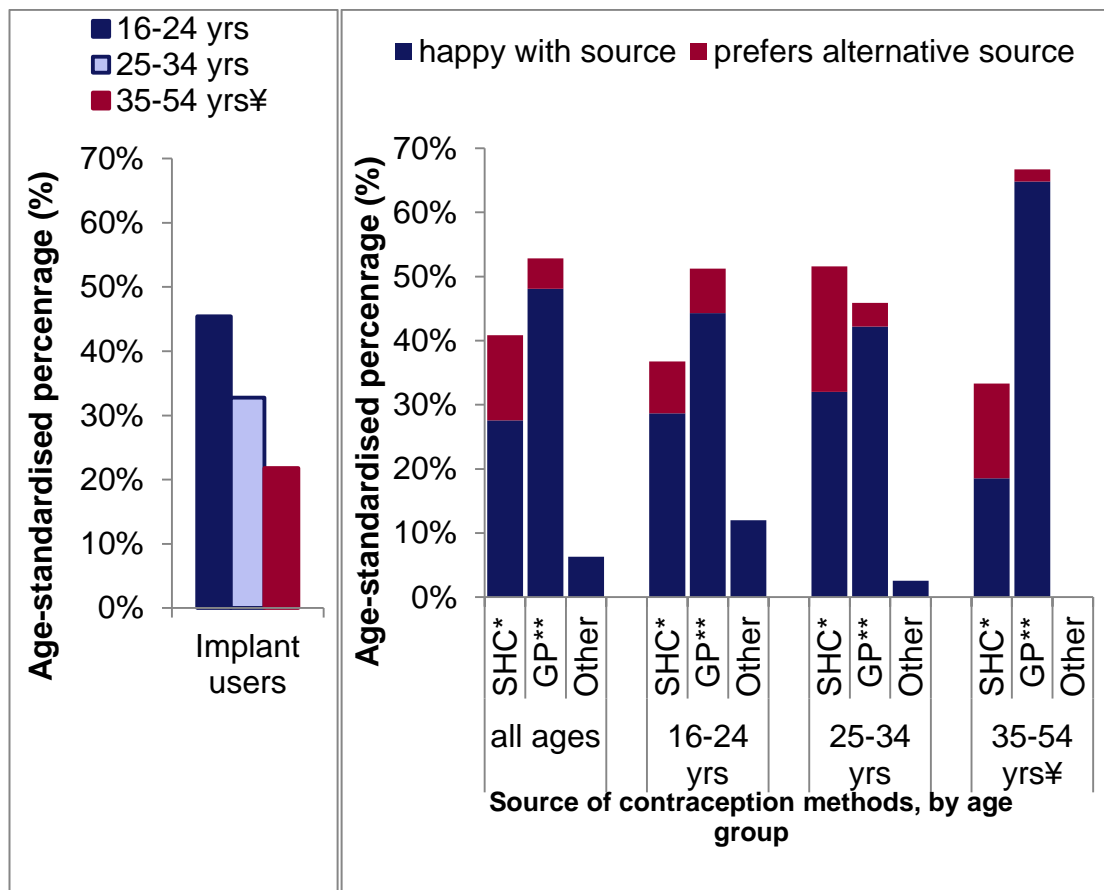


Figure 9: Proportion women at risk for unplanned pregnancy who were using implants who were satisfied or preferred alternative source of implants, by age group, England, 2017 (n=187)

SHC* refers to Sexual Health Clinic which includes GUM clinic, family planning clinic, contraceptive clinic, reproductive health clinic. Refers to your general practitioner or practice nurse
 Due to very low number of women aged 45-54 years using implants, the graph presents women aged 35-54 years as one age group.
 Overall age distribution of implant users will not correspond to Figure 9 where proportion of different methods add up to 100%.

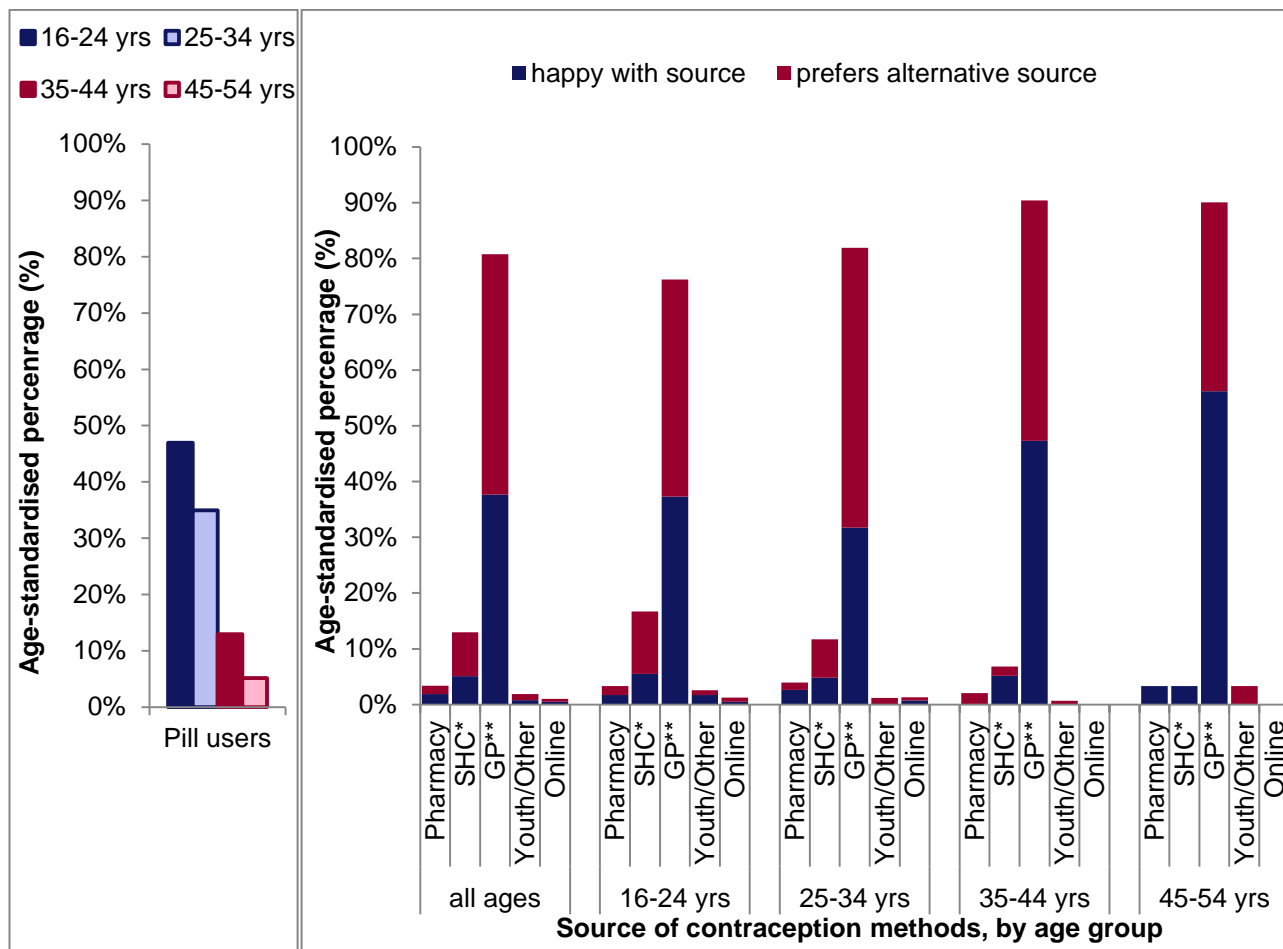


Figure 10: Actual vs preferred source for contraceptive pill among women at risk for unplanned pregnancy by age group, England, 2017 (n=834)

SHC* refers to Sexual Health Clinic which include GUM clinic, family planning clinic, contraceptive clinic, reproductive health clinic. GP** refers to your general practitioner or practice nurse from your general practice.

For longer acting methods of contraception, younger women were relatively more likely to use SHCs than older women who tended to see their GP. Women using the GP were generally most satisfied with their place of care. Women who had an unmet need for contraception (not using contraception, heterosexually active, fertile and not wanting to be pregnant) were most likely to say that they would visit their GP in the future if they wanted to obtain supplies.

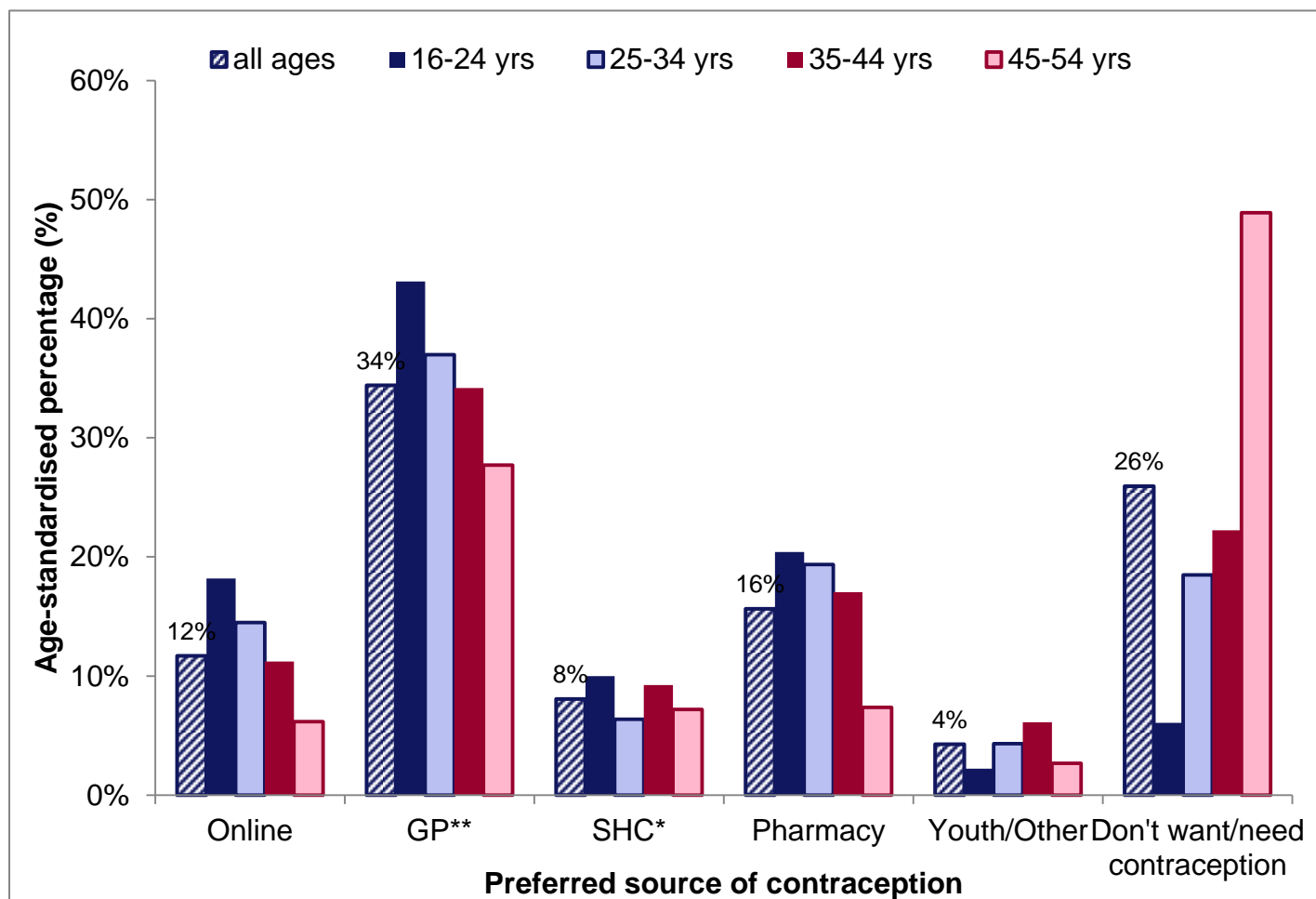


Figure 11: Preferred source for contraception among women who were not on contraception and at risk for unplanned pregnancy by age group, England, 2017 (n=712)

SHC* refers to Sexual Health Clinic which include GUM clinic, family planning clinic, contraceptive clinic, reproductive health clinic. GP** refers to your general practitioner or practice nurse from your general practice.

Reproductive Symptoms

Four out of 5 women experienced at least one reproductive health symptom in the last 12 months. This was more common at the extremes of reproductive life (age 16 to 24 or 45 to 54). Menstrual issues were reported by half of women in all age groups and three quarters of women in the 16 to 24 year old age group. Menopausal symptoms were reported by more than half of women over 45 (Figure 12).

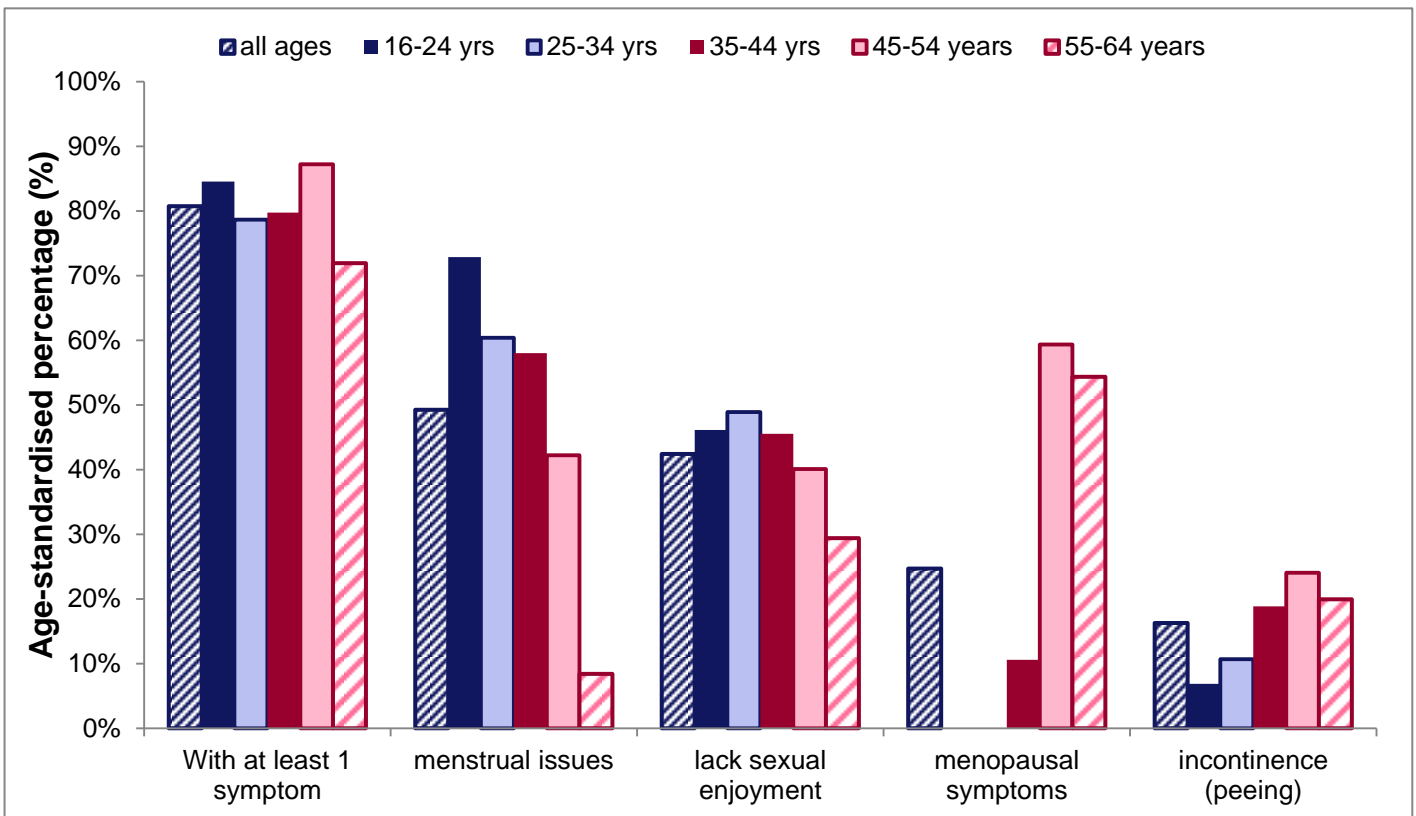


Figure 12: Reproductive health symptoms experienced in the last 12 months, by age group, England 2017 (n=6,218)

Reproductive symptoms often affected women’s ability to carry out their daily activities but symptoms were often concealed, particularly from work colleagues

“I never did say to work, that I was off because of period pain because I worked for years in a very male dominated banking environment...I felt there was an issue of stigma with saying I was off...I would have to invent reasons month after month and soldier on and dose myself up and try and get through the days best you could. Then collapse when you go home.”

Less than half of women with symptoms sought help although this was not related to reported symptom severity (Figure 13).

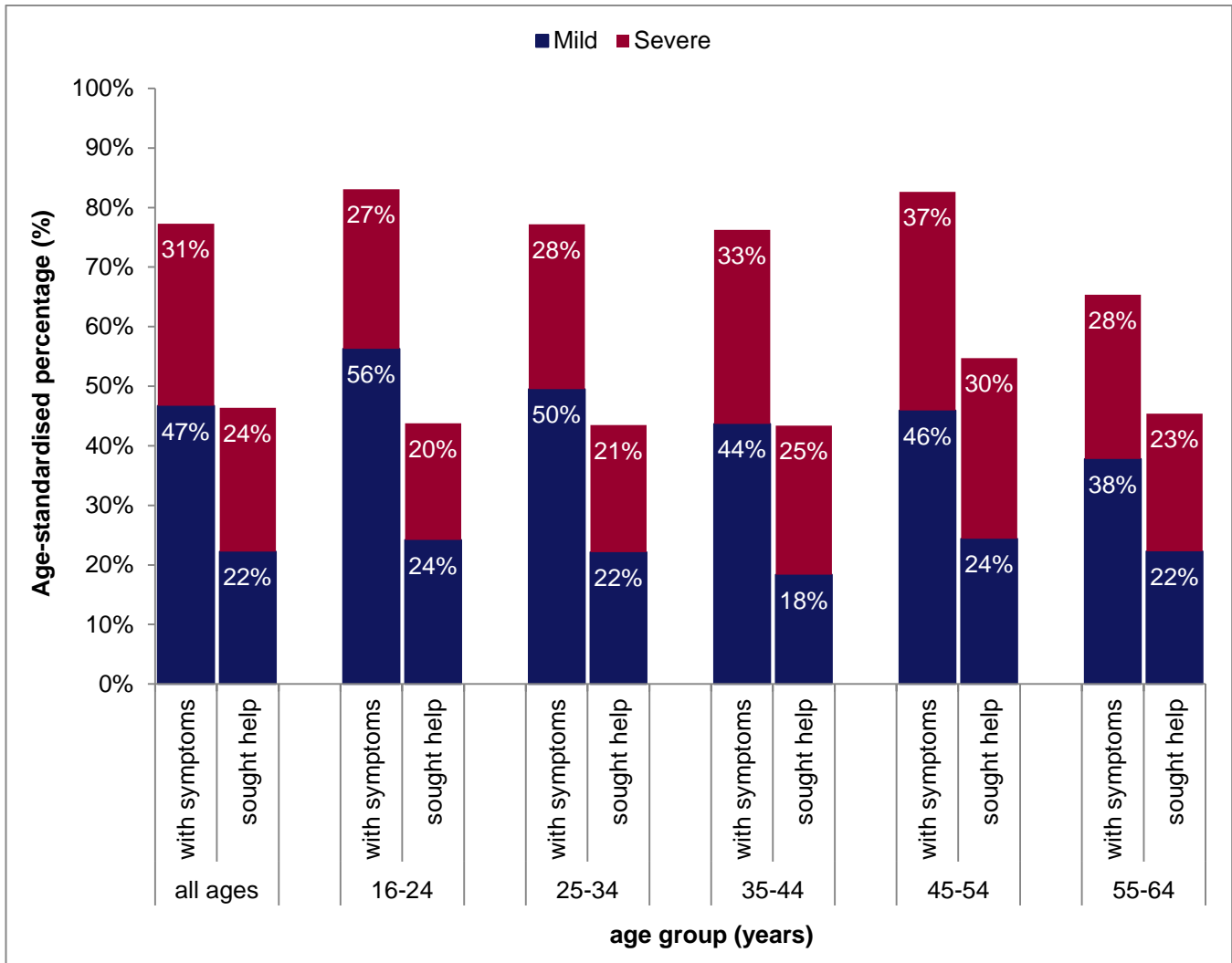


Figure 13: Help-seeking behaviour by severity of reproductive health symptoms and age group, England 2017

Symptoms in the postnatal period were particularly prevalent with more than 80% reporting at least one symptom including difficulties with breastfeeding (45%), lack of sexual enjoyment (45%), incontinence (26%), and baby blues (26%) or post-natal depression (19%). Baby blues and depression were more common in younger age groups notably the 16 to 24 year old age group. Less than a third of women with postnatal symptoms sought help for their symptoms and those aged 16 to 24 were the least likely to seek help (Figure 14).

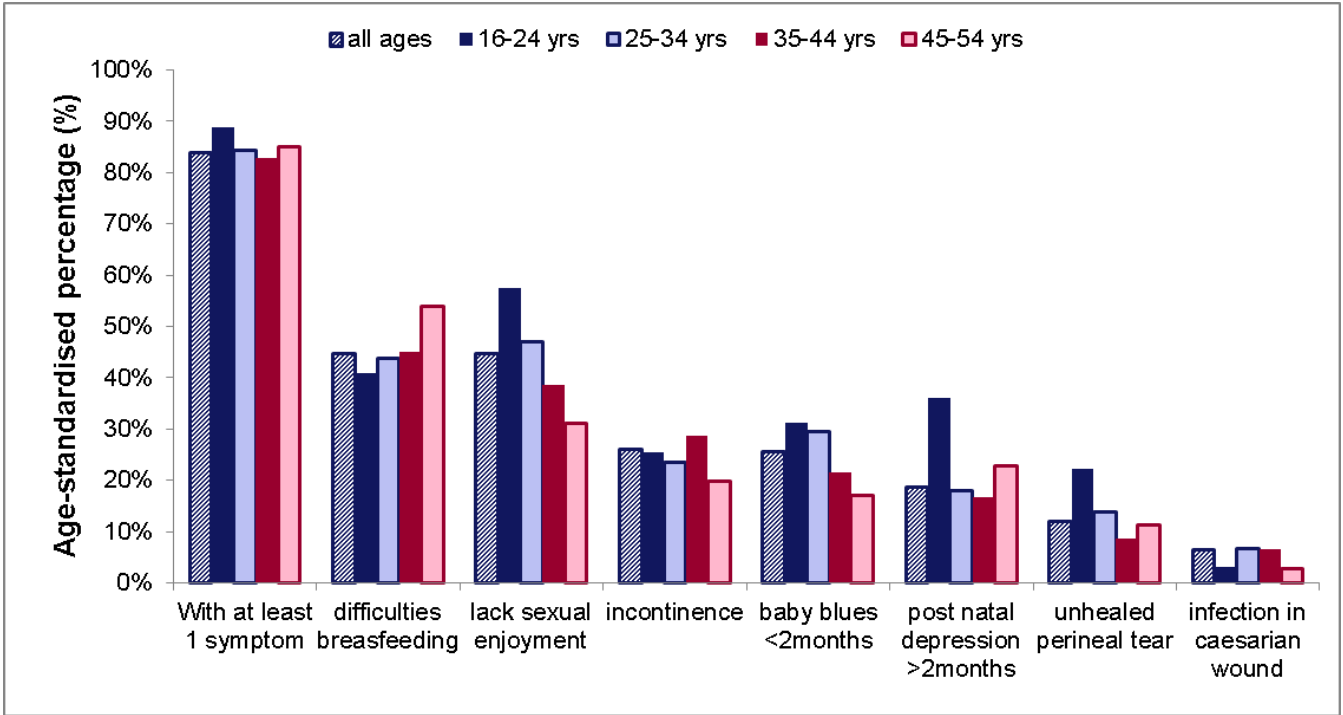


Figure 14: Post natal symptoms ever experienced by age group in England (n=1,512)

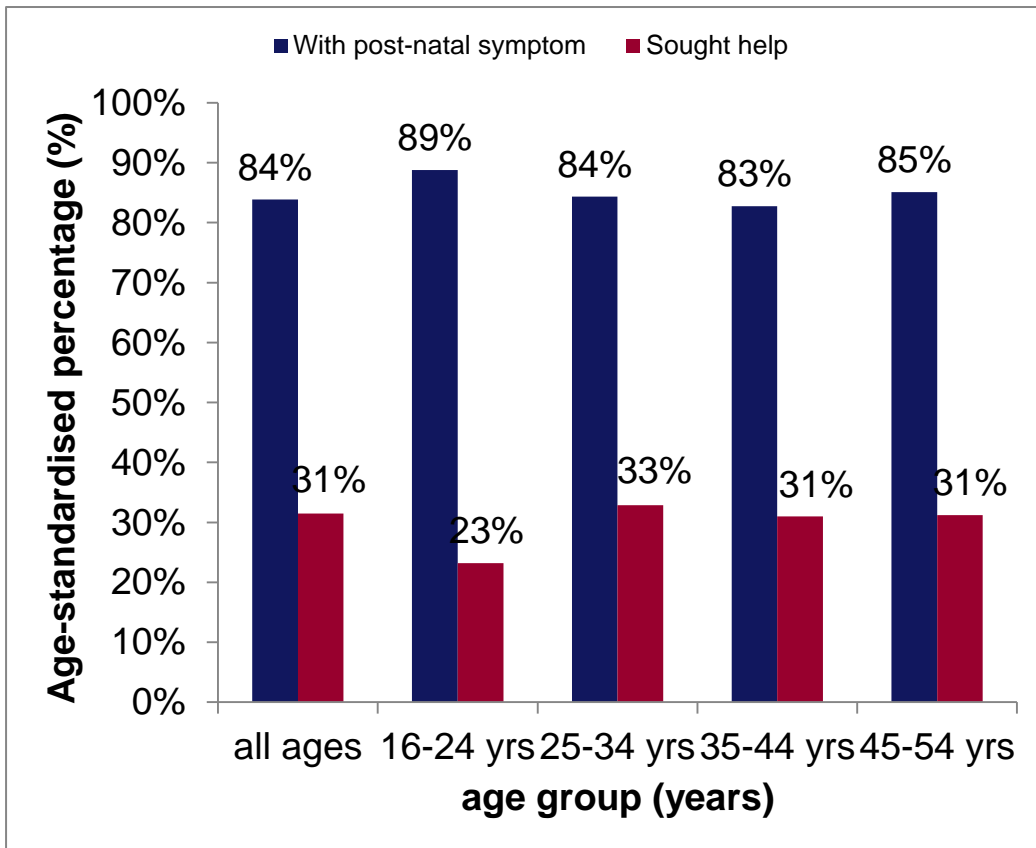


Figure 15: Help-seeking behaviour among women who ever experienced post natal symptoms, after giving birth in the last 5 years, by age group in England (n=1,512)

Embarrassment commonly acted as a barrier to accessing knowledge or support. There was often a perception that symptoms were normal and should be endured and consequently women feared they might not be taken seriously or that they would be judged negatively for needing help.

“Although he was unplanned, and I’d accepted I’m going to have him, when he was born I didn’t want to dress him up, I didn’t want people to come and look at him, I wasn’t smiling...there was something wrong with me and I knew it but I was too embarrassed to tell anyone...”

“I was told by a school nurse when I was 13 when I would be almost fainting, be physically sick with the pain (of menstruation), ‘oh you just need to go outside and have a run around. You need to be more active. Just get used to it.’

“...the whole of the symptoms of the menopause, depression, anxiety, hot flushes, sleepless nights, you feel yourself worthless...it’s a horrible state. And you come back to your GP and she’s telling you ‘no, it’s normal. Just get on with your life.’

However, participants had very different experiences and described differing levels of confidence in their healthcare providers’ knowledge of reproductive health issues. Feeling well cared for by a healthcare professional in an environment free of judgement was seen as an essential component of good care in order to help overcome barriers to asking for help.

“...it must be difficult the amount of pressure on GP surgeries but acknowledge each person you talk to as a human being for whatever (time) you have...”

“...creating ways to support people because some of the existing ways...are not working.”

Discussion

Reproductive wellbeing for women throughout life is multi-faceted and findings from the focus groups and online survey demonstrate that women's lives are affected significantly by a wide range of reproductive health issues. There is a juxtaposition between the need to plan and/or prevent pregnancy across the lifecycle against the day-to-day realities of managing symptoms associated with reproductive functions such as periods, the menopause and the impacts of childbirth. Because these are all part of a normal lifecycle, reproductive difficulties or morbidities can be under-reported and overlooked by wider society.

Women's reproductive health priorities change with age and how women view and manage these priorities is affected by their source of reproductive health education and information. School remains the most important source of information but the internet is increasingly relevant for younger women.

Patterns of service use differ with age and the nature of the issue. Importantly, significant proportions of women experiencing reproductive health symptoms do not seek care even when those women described their symptoms as severe. Contraception service use also varies with age and the method of contraception women are using. Overall most women are happy with their source of contraception but a significant proportion of women we surveyed would have prefer to access different services.

Conclusion

Detailing women's experience of their reproductive health has shown that the majority of women do experience some difficulties related to reproductive health at different stages in their life and would benefit from easily accessible information an enabling environment for making positive choices, managing symptoms and reaching care when needed. In order to ensure that women of all ages and backgrounds can take the steps required to take control and manage their reproductive health education, support and services should be structured and delivered in a manner that reduces barriers and reflects the needs of populations they serve.

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