

# Innovating for Improvement

## Contraceptive Conversations: ‘The Pill or What’

SH:24



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## About the project

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### **Project title:**

Contraceptive conversations: The Pill or What?

### **Lead organisation:**

SH:24

### **Partner organisation(s):**

### **Project lead(s):**

Paula Baraitser

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## Part 1: Abstract

Women spend up to 30 years using contraception. Choosing the right method is a process and requires accurate information and personal support. However, clinical consultations are too short and too infrequent; friends have experience of a limited range of methods; websites are insufficiently personalised and online forums can be overwhelming and may contain inaccurate information.

We used a process of human centred design to develop a dedicated, safe and anonymous space for people to access a combination of peer experience, accurate information and clinical advice, 24/7, to support effective contraceptive problem-solving.

The 'Pill or What?' was launched on the 01/09/2018. It demonstrates the feasibility of delivering personalized contraceptive information through a clinically moderated online discussion forum. The forum receives 1,500 views per day and 80,000/month. During November, 80 active users (excluding staff) generated 101 posts. On average, each user viewed 4 topics (range 1-27), read 12 posts within those topics (range 0-106) with an average read time of 5 mins (range 0-37).

Qualitative analysis of the content of the posts identified 4 themes:

1. The discussion forum personalizes and dramatizes information about contraception, making it more engaging.
2. The forum highlights the structure of contraceptive decision making as a process that continues over long periods and is iterative and reflexive.
3. The discussion forum puts clinical information and user experience side by side, throwing into relief different priorities and perspectives and particularly the limits of the available clinical information as a resource to inform decisions about contraception.
4. Many posts asked clinical questions and clinical answers appeared to be viewed as definitive, often closing down the discussion.

This pilot demonstrated the possibilities of providing clinical advice outside the traditional format of a clinical consultation. It suggests new options for combined clinician/service discussions that go beyond the traditional one-to-one or face-to-face formats.

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# Contraception?

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[Order a free test](#)



**SH:24**

Discreet service

Talk to us by text

Accessing our services

[Order a free test](#)

**SH:24 provides free and confidential sexual and reproductive health services 24 hours a day.**

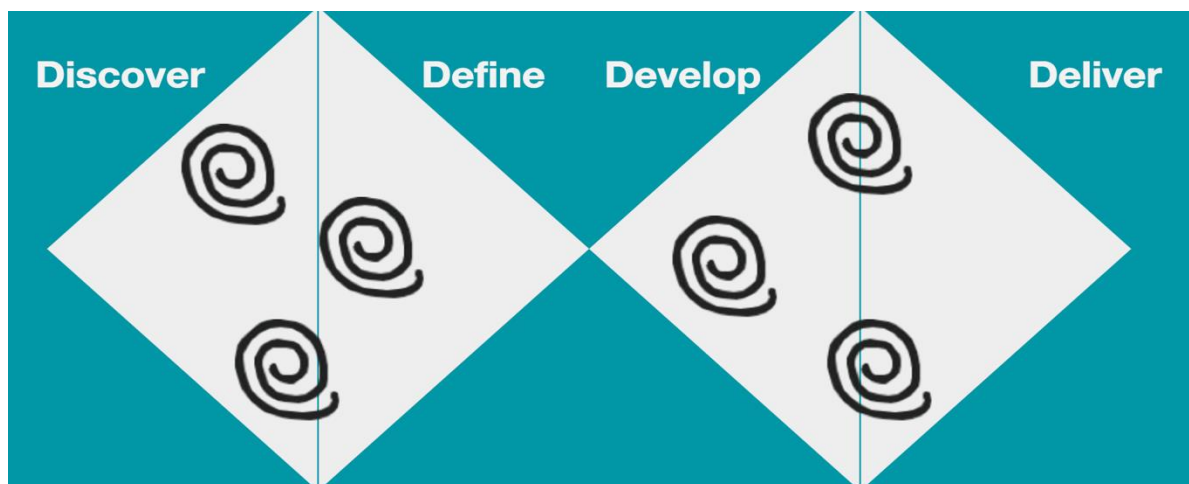
- [STI tests](#) for chlamydia, gonorrhoea, syphilis & HIV
- [diagnosis and treatment](#) for genital warts and genital herpes
- [oral contraception](#)
- [learn about STIs](#)
- [compare contraception methods.](#)

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## Part 2: Progress and outcomes

Our intervention is a dedicated, safe and anonymous space to access a combination of peer experience, accurate information and clinical advice, 24/7, to support effective contraceptive problem-solving. It is innovative in supporting hybrid conversations that combine the creativity and accessibility of social networking with accurate clinical advice.

We followed a [‘Double Diamond’ framework](#) (Design Council, 2015), [a four-stage design process - discover, define, develop and deliver](#).



The discovery process involved benchmarking (taking ideas from others), fieldwork (collecting small amounts of ethnographic data to generate assumptions) and the development and testing of assumptions.

Our benchmarking work involved analysis of discussion forums where people were talking about contraception. [We reviewed sites in Australia \(betterhealth, whatcontraceptiveareyou\); USA \(Bedsider, sexualityandu\); South Africa \(health24; MSI\); UK \(talkchoice, netmums, BBC, SXT, Lloyds, Brook, NHSChoices, patient.info; mumsnet, BPAS\).](#) We found lists of questions, often repeated; [limited searchability](#); shared [user experience](#); [inaccurate information](#); [few resources](#) and [clinical responses that end conversations rather than joining them](#). We completed fieldwork with women in contraceptive clinic situations and outside. We observed consultations, spoke informally to women in the clinic waiting room ran a small twitter poll, and completed focus group discussions with 106 women recruited through twitter and Facebook.

## CAN YOU HELP CHANGE CONTRACEPTIVE CONVERSATIONS?

Back in August we wrote about an [exciting new service we're planning to develop](#) - a safe space online where people can have conversations about their experiences of contraception, which will be combined with clinical facilitation from an SH24 contraceptive consultant.

We've now started developing the service, which we're hoping to launch in April next year, and we want you to get involved!

Meet Maja, a service designer working on the initial "discovery" phase of the project. Maja's job is to try to understand what you all need from a service like this. The first step for her is to speak to as many of you as possible about how you manage (or don't manage!) your contraception.

If you'd be up for spending half an hour on the phone with Maja to help us to build this exciting new service, email her your number at [sh24.info@nhs.net](mailto:sh24.info@nhs.net). We'd really love to hear from people outside of London - though of course, Londoners are still very welcome so if you can share widely we'd be really grateful.



The discovery process enabled us to define our assumptions about how and why women might use our intervention:

- Fear about health risks and effect on lifestyle are important reasons for not starting a method.
- Side effects and worry about fertility are important reasons for stopping a method.
- Users feel they have few options and limited information about contraceptive options
- Users want to be better informed about all the contraceptive options
- Users seek more personalisation and less medical language in the information that is available to them.
- Users are unaware of what is normal when coming off the contraceptive pill
- Users will want to hear from 'others like me'
- Users are put off when contradictory information is posted in a thread
- Users are concerned about privacy about being identified on a platform
- Users will want to share things they find on the platform with others
- Users want the opportunity to direct message with a clinician or certified super-user
- Users will be keen to engage with other people's questions as well as looking for answers to their own
- Users are looking for clinically moderated discussions



### Define

On the basis of these assumptions we defined our intervention as an open access discussion forum with clinical moderation. We agreed that anyone could view the forum but that posting required a simple process for making an account that involved email verification. Users could choose their own user name to protect their anonymity.

### Develop

We developed and tested a series of prototypes and iterated in response to feedback including identifying an appropriate 'off the shelf' discussion forum, customising it to our needs and developing a visual identity for the forum. We worked with users to generate content to pre-populate the forum, identifying frequently asked questions and developing appropriate responses. This process was important in agreeing the 'tone of voice' for the forum. We created a structure to maximise searchability with posts structured within topics and a clinical 'top pick' every few days to add value to current discussions.



Deliver

The alpha site went live on 01/09/18. In the optimisation phase, we experimented with: the tone of the posts, the rapidity of the clinical response; the development of the 'top picks' function to curate content on the site – summarising, adding to and reflecting on current discussions. We promoted the site via social media (Facebook and Instagram), Google 'adwords' and links from the main SH:24 website.



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SH:24 @sh24\_nhs · Oct 30

In this week's top pick from [ThePillOrWhat.org](https://ThePillOrWhat.org), our new contraception forum, Dr Paula Baraitser shares more ways to take the combined pill – and bleed less: [bit.ly/NewWaysforPill](https://bit.ly/NewWaysforPill) Read, share and talk to other users and clinicians at #ThePOW #thepillorwhat



### Analysis

We evaluated the intervention through the built-in metrics function of the discussion forum software (discourse.org) to show numbers of users and patterns of use. We used content analysis to describe conversations the topics of discussion and to explore the role of the forum in relation to alternative strategies for accessing similar content, for example information pages, clinical consultations or conversations with friends. We read and re-read the posts and discussed them in groups to develop themes. We then re-read the posts looking specifically for material that was inconsistent with our conclusions and then worked to modify the themes to incorporate or explain this material.

### Results

The 'Pill or What?' was launched on the 01/09/2018. It demonstrates the feasibility of delivering personalized contraceptive information through a clinically moderated online discussion forum. The forum receives 1,500 views per day and approximately 80,000/month. During November 2018, 80 active users (excluding staff) generated 101 posts. On average, each user viewed 4 topics (range 1-27), read 12 posts within those topics (range 0-106) with a read time of 5 mins (range 0-37). New user sign ups during November, 2018 ranged from 0-6/day.

## Community health

Month NOV 9 - DEC

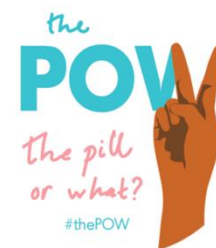


The qualitative analysis identified 4 themes:

- The discussion forum personalizes and dramatizes information about contraception.
- The forum highlights the structure of contraceptive decision making as a process that continues over long periods and is iterative and reflexive.
- The discussion forum puts clinical information and user experience side by side, throwing into relief different priorities and perspectives and particularly the limits of the available clinical information as a resource to inform decisions about contraception.
- Many posts asked clinical questions and clinical answers appeared to be viewed as definitive, often closing down the discussion.

Read, share and discuss everything contraception

Ask a question



all categories ▾ Categories **Latest** Top + New Topic

Topic	Category	Replies	Views	Activity
Case study: I don't like to change something if it's working case-study	Combined pill	4	4.4k	17d
Are the Horror Stories True? 2. The risks and benefits of the copper IUD	Dr. Paula's Top Pick	2	4.2k	Oct 26
Can the hormonal coil cause mental health issues?	Hormonal coil (IUS)	4	3.0k	12d
Are the horror stories true?	Non-hormonal coil (IUD)	15	1.4k	Nov 5

### Part 3: Cost impact

The 'Pill or What' discussion forum is provided by the community interest company SH:24 as part of its online sexual health service provision. We see this type of information and support as an essential element of online health service provision, providing 'wrap around' clinical support for self-management in sexual health. Self-care is associated with increased work on the part of service users and requires new information and skills. In this context, clinical support is increasingly important and new ways of providing this support are required. We feel that self-management should not mean unsupported. The forum offers timely answers to clinical questions in a supportive environment. It is highly efficient in that it delivers information to large numbers of people with limited clinical input as the ratio of views to posts is very high. In this way, it is an important addition to a suite of information resources that include information pages, videos and podcasts, SMS conversations, webchat and the discussion forum. Because of its facility to offer engaging and interactive information, the discussion forum has been 'mainstreamed' into our standard service offer. Its open accessibility demonstrates our vision of improving sexual health for everyone. We plan to develop and expand this approach to clinical support to complement all of our online services.

## Part 4: Learning from your project

The project was completed as planned and to budget. The learning from this project comes from the analysis of the use of the forum. The key learning points are:

1. The discussion forum personalizes and dramatizes information about contraception.
2. The forum highlights the structure of contraceptive decision making as a process that continues over long periods and is iterative and reflexive.
3. The discussion forum puts clinical information and user experience side by side, throwing into relief different priorities and perspectives and particularly the limits of the available clinical information as a resource to inform decisions about contraception.
4. Many posts asked clinical questions and clinical answers appeared to be viewed as definitive, often closing down the discussion.

The discussion forum personalises and dramatizes information as users narrate their contraceptive journeys and experiences, both positive and negative. It locates the decision within a process of trial and error with previous experience with contraceptive methods a fundamental element of this discourse. This is very different from the clinical discourse that provides data on the risk of each side effect on each method.

*'I once had the implant but after 6 months bled continually and had to take the pill at the same time so they removed it. .... I have considered the mini pill but am struggling to tell if that is the same hormones as the implant and if I am likely to bleed with that too.'*

*'I would just like to say how much I love the implant. I have been using the implant for seven years. That's right - I'm on my 3rd one! I was originally taking the pill but worried all the time about getting pregnant. When I went to see the Dr about using the injection, she recommended the implant. I've never looked back!'*

*I was on the implant for 8 years (3 implants). It was great, stopped my periods and no complications - no side effects, nothing. When I flew to Tanzania in March, I started to get heavy bleeding – really irregular, all over the place so I took the implant out.*

*(Text has been modified to protect anonymity)*

By juxtaposing user experience and clinical advice, the forum highlights the discrepancy between research evidence and user experience. The forum gives equal weight to these posts, inviting input from users with similar experiences in a way that is difficult in a clinical consultation where clinical perspectives are systematically prioritised and there are no other users present.

*A recent review of 26 studies that looked at the relationship between depression and progestogen only methods of contraception found no association except for the study mentioned above (Dr Paula).*

*I think this is definitely something that needs to be looked into by professionals because before i was on sertraline I was on the pill and my anxiety was bad then too. It got better when I stopped (Forum user).*

The forum demonstrates the possibilities of providing clinical advice outside the traditional format of a clinical consultation. It offers a new form of clinical interaction with similarities to group consultations and telehealth interventions that disrupt traditional one-to-one and face-to-face models of care. The discussion forum provides information and advice before and after a clinical consultation, answering questions prior to an intervention or prescription or providing information about problems experienced afterwards. It acknowledges that information provision happens iteratively over time and that traditional consultations are too compressed to deliver all of the information required or to surface all the questions that a user may wish to ask.

*I recently had a hormone coil fitted – when is it OK to use a tampon?*

*I was prescribed the pill last week and I have had bleeding ever since I started taking it – what should I do?*

## Part 5: Sustainability and spread

Yes, this intervention will be sustained beyond the funding period. Commitment to sustaining it was agreed within SH:24 prior to the start of the project. SH:24 recently won the Guardian Public Service Award in the digital and technology category and a Queens Award for Enterprise for its work in revolutionizing sexual health services nationwide. This intervention is very much part of this work. The intervention has been publicised through a social media campaign on Facebook, Twitter and Instagram. It will be featured in a pod cast on contraceptive decision making. We plan to expand and extend this model of clinical conversation to include discussions of sexual health and the menopause. This work has had influence beyond the UK with pilots of similar services under discussion in Tanzania and Kenya.