|  |  |
| --- | --- |
| **Participant ID** | **Q1. Please state your age** |
| 1 | 27 |
| 2 | 24 |
| 3 | 41 |
| 4 | 48 |
| 5 | 26 |
| 6 | 31 |
| 7 | 33 |
| 8 | 34 |
| 9 | 46 |
| 10 | 32 |
| 11 | 33 |
| 12 | 26 |
| 13 | 30 |
| 14 | 38 |
| 15 | 23 |
| 16 | 24 |
| 17 | 28 |
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| 19 | 21 |
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| 22 | 22 |
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| 24 | 23 |
| 25 | 23 |
| 26 | 20 |
| 27 | 41 |
| 28 | 23 |
| 29 | 20 |
| 30 | 22 |
| 31 | 20 |
| 32 | 28 |
| 33 | 38 |
|  | **Q2. Please select whether you have been diagnosed with endometriosis or whether you are in the process of obtaining a diagnosis.** |
| 1 | Waiting  |
| 2 | Waiting  |
| 3 | Waiting  |
| 4 | Diagnosed |
| 5 | Diagnosed  |
| 6 | Diagnosed  |
| 7 | Diagnosed  |
| 8 | Diagnosed  |
| 9 | Diagnosed  |
| 10 | Diagnosed  |
| 11 | Waiting  |
| 12 | Diagnosed |
| 13 | Diagnosed  |
| 14 | Diagnosed  |
| 15 | Diagnosed  |
| 16 | Waiting  |
| 17 | Diagnosed  |
| 18 | Waiting  |
| 19 | Waiting  |
| 20 | Waiting  |
| 21 | Diagnosed  |
| 22 | Waiting  |
| 23 | Diagnosed  |
| 24 | Diagnosed  |
| 25 | Diagnosed  |
| 26 | Waiting  |
| 27 | Diagnosed  |
| 28 | Waiting  |
| 29 | Waiting  |
| 30 | Diagnosed  |
| 31 | Diagnosed  |
| 32 | Diagnosed  |
| 33 | Diagnosed  |
|  | **Q3. Do you believe women are offered a sufficient range of effective pain management treatment options, both medical and non-medical, or are more options needed in order to further improve women’s management of pain caused by endometriosis? Please explain your response.**  |
| 1 | Not at all. Pain is not usually believed when it is in reference to periods. From personal experience, I have not had support or appropriate pain management outside of OTC painkillers and self-care advice, which do not work for my level of pain. I have also had pain management be refused due to normalised opinions of period pain in general and due to being overweight. More support, levels of understanding and even compassion are needed for those who either have endometriosis or are waiting for a diagnosis of endometriosis as pain is an individual experience and endometriosis is not a one size fits all situation |
| 2 | Definitely not - just keep being offered contraceptive pills, which are not anywhere near worth the all the side effects. Those pills also just cover up the symptoms of certain conditions instead of treating them - making the condition worse in the long term. Standard painkillers, such as paracetamol are ineffective against endometriosis pain, and nothing else is offered. Doctors don’t suggest management strategies, such as yoga, meditation and dietary changes (reducing gluten/dairy) that have been shown to help - instead, these are things that women learn from social media/reading up on management of the condition.  |
| 3 | As I speak with a different GP each time my symptoms worsen, I don't feel there is a holistic approach. I've not been offered any alternatives to drugs. And despite the chronic nature of my pain, I'm kept on short doses, meaning I'm forever chasing the doctors surgery for another prescription.  |
| 4 | I haven’t been offered any.  |
| 5 | I don’t think women are offered enough. I think doctors work on a list of things which are seen as ‘good for treating endometriosis’ but in reality everyone is different and endometriosis affects different organs too. For example, my bowel and bladder are affected by endometriosis and the generic pain medications given out don’t always help because they’re broad and not specific! Everyone is different and I think there needs to be broader help, especially with medical treatments.  |
| 6 | No, I have suffered severe symptoms for more than 15 years and have never seen anyone who specialises in pain management. The only options I have been offered is contraceptive or mild pain killers  |
| 7 | No, I don't think endo pain is taken seriously by some professionals. I have requested a hysterotomy as I have one child and don't want any more and this has been refused due to my age.  |
| 8 | At first I was not given any options before I was diagnosed properly, it improved a little with diagnosis, it would have been useful to know about all options really from the outset.   |
| 9 | No. My painful periods were normalised from the age of 11. From the first symptoms of endo at 22, it took me 12 years to get a diagnosis - I was variously told that the pain was “due to the way you walk”, was “just period pain” and - after diagnosis, that I should have a baby to fix it.  |
| 10 | Based on my personal experience alone, no. I would have much appreciated more options upon my first visit with my specialist. At the time, I was exclusively offered a treatment option called Visanne - a progestin pill. If I had known what my options were before being told this was the only one, I would have chosen not to begin with this treatment specifically.  |
| 11 | No. There are only two long-term options for pain relief medication, both of which have horrendous side effects. Other methods or other types of painkiller should be made available to try. I have not been offered any non-medical firms of pain relief.  |
| 12 | To a certain extent, I feel like it is still up to women to look for information, especially online - especially on social media. My OB gyn prescribed painkillers and suggested dietary adjustments and regular exercise (I am on the contraceptive pill). However I feel like this is not enough, especially when it comes to painful sex and adenomyosis. You just have to deal with it and smile through the pain...  |
| 13 | I haven’t experienced a range of treatment options personally because my symptoms subsided after trying the first medical option (doubling my daily dosage of the contraceptive pill). I wasn’t aware at the time that there even might be a range of other options.  |
| 14 | There is not enough services available for endometriosis pain management physically and mentally, this is not only due to GPS having a lack of knowledge and understanding but the NHS itself has very little funding for these services. Right now I live in NI part of the UK and there is no endometriosis specialists available for my care. I've been told that I'm going to be operated on by a gynaecologist who has operated on endometriosis before but is not a specialist and I have extensive endometriosis with bowel involvement. I was given peppermint tablets for my endometriosis pain and told it was stress related IBS and advised to go onto antidepressants. I was medically gaslighted regarding my pain and told I must have a low pain threshold prior to my diagnosis in 2008 at the age of 26  |
| 15 | More options are needed, and better communication between gynaecology clinics/endometriosis consultants and pain management specialists.  |
| 16 | I do not feel we are offered sufficient management options. I have frequently been told by GPs that my pain is ‘normal’ and to just take a paracetamol (which isn’t at all effective). The only other option I’ve been given is to take the pill back to back until I want to have a child.  |
| 17 | No, they didn’t believe how much pain I was in  |
| 18 | I was given very strong pain killers to take whenever I felt I needed them but it wasn’t an effective method and I didn’t want to have to rely on these pain killers everywhere I went. I was also made to go on the pill to minimise pain which it did but I was fully against going on the pill again as even though I wasn’t having the crazy pains, I had bad mental health, felt sick 24/7 and it just negatively impacted me and I’ve stopped taking it now. More options are 1000% needed, these current options are definitely something to just keep us quiet for as long as possible  |
| 19 | No, women are not offered enough. In fact, I have been offered little to no pain management options throughout the process of my endometriosis journey.  |
| 20 | The only pain management I’ve ever been offered is contraception such as the pill but I can’t have an estrogen based pill due to other medical issues so this limits the pain management that is available to me  |
| 21 | I think the options are there, just getting a diagnosis is hard. Although when it’s really bad paracetamol/ibuprofen arent enough, so the option for something stronger in a bad case needs to be an option, though I understand this may be abused/cause addiction  |
| 22 | No there is not enough support for any part of the process. Women’s health is seen as a joke and there is such a lack of research therefore women are not believed and there is pretty much no support in diagnosis and management.  |
| 23 | My personal experience is no. I was offered no sort of pain management at all including pain killers. But I know some people who has had pelvic floor physio, strong pain killers etc. Then again...many people are constantly going to A&E because of pain. More things need to be done.  |
| 24 | I was never offered any pain management until I specifically asked for it. I would explain how painful my periods were etc and at no point was I offered anything other than the contraceptive pill.  |
| 25 | Not sufficient solutions! The strong medication has massive impact on day to day life that is not necessarily better than what they’re “masking” and often you’re waiting months to even get said medication as they pass it off as mental health issues, ibs or other  |
| 26 | A lot of the time the contraceptive pill is offered but that does little to help the actual problem. I just feel like doctors are quick to offer that as a solution without actually getting to the root of the problem.  |
| 27 | Not at all,in my opinion contraception is the only main form of so called pain relief offered followed by surgery. I'm now under chronic pain team for my pain relief as gynaecology could not offer this type of pain relief.  |
| 28 | Definitely not. I have been menstruating since I was 10 and was continuously told that the I would outgrow the excruciating pain (to the point of passing out) that I experienced. I was not referred to properly be diagnosed for endo until a few months ago.  |
| 29 | I have been offered a lot of pain management, which I have accepted however it does not seem to work as the pain can be so bad. I do not feel this is down to medical staff refusing to prescribe me pain medication, but down to the pain itself being so severe. I have not yet been offered surgery but have been told it may be an option.  |
| 30 | There are lots of options offered for medical pain management. However this is sometimes used as a means of staving off giving more help by doctors which makes it ineffective. It's as though they think by giving you never ending pain relief they don't think they need to help anymore. More could be done to offer non medical and medical relief in equal standards to help more.  |
| 31 | Definitely more options needed in both medicinal pain relief and natural techniques to alleviate symptoms  |
| 32 | Absolutely not, more options are needed. My medication only reduces my pain doesn't eliminate it  |
| 33 | More options are needed. No medical professional ever suggested a TENS machine for endometriosis pain, but I figured it out myself. It's simply not good enough to expect women to manage on contraceptive pills and injections, without monitoring of the symptoms of endometriosis as a chronic pain condition.  |
|  | **Q4. The management of endometriosis with medication is one of the most common forms of initial treatment both before and after an official diagnosis.** **Have you been offered or experienced using medication such as hormone therapy, contraceptives, or anti-inflammatory painkillers as a form of treatment and do you feel like this was or would be an effective way to manage your pain?** **Do you have any concerns about this treatment?** |
| 1 | I have been on hormonal contraception for the better part of 10 years to attempt to manage my pain. I have also used generic over the counter painkillers as well as being prescribed mefenamic acid, however I am now at the stage of pain and possible disease progression that these have not worked for my period/ovulation pain for a number of years yet the GPs were reluctant to do anything more until I became very unwell a year ago. I am currently 9 months into using the contraceptive implant and for the first 3 months, I had no pain at all and I could live life properly but the pain has unfortunately returned and I am concerned that GPs do not have the appropriate training for what to do when something that "should" work doesn't. This has left me now in limbo as the GP cannot sign off on anything anymore without the consent of a specialist (waiting for the referral to be official). I am still waiting for a endometriosis consultation to know what pain management is available to me knowing how my pain has progressed but I have had suggestions of hormone suppression due to traditional and contraceptive hormone treatments not working like they should.  |
| 2 | I haven’t had the diagnosis yet, but I’m almost certain I do have endometriosis. My gp said that contraceptives are used to treat it, but I know that is incorrect - as they do not treat the condition and just cover up the symptoms and have too many unjustifiable side effects. I do have a diagnosis of PCOS and was also offered contraceptives then, which I tried - and experienced too many negative side effects, and told my gp that I would never go on contraceptives again.  |
| 3 | I've taken ibruprofen and I don't have concerns about this. I haven't been offered or considered hormone related drugs.  |
| 4 | Yes contraceptives. Apart from the side effects no concerns.  |
| 5 | After being prescribed over 8 different contraceptives, a few different anti-inflammatory medications, painkillers and then finally hormone therapy my body had just had too much and started to really get confused. Changing the contraception often messed with my natural cycle and made periods much worse, sometimes caused me to miss periods and sometimes even caused breakthrough bleeding. The levels of hormones changing affected my mental health too so not only was I worried about pain I then had to be concerned about my mental health due to so many hormonal changes. It’s not effective and has a huge impact on day to day life. In my opinion it made the endometriosis more painful. The hormone therapy helped a little with the pain but of course came with its own consequences. I think it’s only effective when a great plan is put into place and is tailored to the individual and not just used broadly.  |
| 6 | Yes I have tried contraceptives and anti inflammatories to manage symptoms, I think it can help on a short term basis but it shouldn’t be something we have to rely on for long term use. |
| 7 | I have been prescribed zapain for the pain and discomfort but these make me extremely sleepy so I don't like to take them during the day.  |
| 8 | Have tried the usual painkillers/ anti inflammatory meds, was a little less pain but not continuous. Have tried the pill, with little improvement.  |
| 9 | I was told to have a coil inserted. Despite trying this twice and despite this making my depression much much worse - to the point of being suicidal - I was told to persevere with it.  |
| 10 | I was offered Visanne, as mentioned above. Visanne did help with my endometrial lesions and did shrink them significantly over the 3 years I was on it. Though the side effects were not necessarily worth it for me, and eventually I had asked to try something new. I also tried the Mirenna IUD, which I liked in theory, but unfortunately it perforated my uterus and I had to have it removed. |
| 11 | Yes to all medication I’m currently on all options. They make the pain manageable even if they don’t take the pain away fully.  |
| 12 | Contraceptive pill without suspension (so I don't get my period) When needed, I was advised to use ibuprofen 600 or paracetamol 1000. I usually go for paracetamol because I don't tolerate ibuprofen very much I am not entirely comfortable with the pill because of side-effects, especially (for me) high blood pressure. I am also seeing a therapist and a psychiatrist and take Zoloft 100 mg for an anxiety disorder with agoraphobia and hypocondria. This has not been prescribed for the pain nor advised by my Ob gyn but somehow my hypocondria is related with the pain I have been experiencing over the years and the fact that doctors always ascribed it to anxiety ("you are stressed").  |
| 13 | I doubled my dosage of a progesterone only contraceptive pill. I then had surgery to diagnose but not treat endometriosis. My symptoms of irregular bleeding, post coital bleeding and pain then completely subsided in the weeks and months after. After about a year I then lowered this dosage back down to normal and symptoms have not resumed (several years on). This treatment was effective without any surgery but I was not aware of any other options. I understood that it was suggested by the consultant anecdotally at the time.  |
| 14 | I've used all the above and more. I was put on several different types of Birth control to no benefit in pain reduction, GnRH analogues, anti inflammatories ( the suppository ones were more effective in pain management) prescription only opiates ( they take the edge off by making you slightly sleepy ) These are not long term solutions, even in medical practice opiates should be prescribed for a short period of time but they are not as there is a lack of qualified endometriosis specialists available to perform gold standard endometriosis treatment which is to excise it ( not ablation ) we end up with other symptoms from taking these medications. Addiction, stomach acid issues, stomach ulcers, constipation, unable to drive, unable to socialise, unable to work, depression, weight gain, suicidal ideation, anxiety, unable to try for a baby. The list is endless to be honest  |
| 15 | I take the pill twice a day to manage my symptoms which is effective but does worry me due to the hormones and side effects. I was also on tramadol long term however i have stopped taking it as didn’t want to be on so much medication for a long period  |
| 16 | Contraception I feel is masking my endometriosis and allowing it to develop unresolved. Painkillers have no effect on my pain. I have not been offered anything else despite seeing several GPs and 2 different gynos. I have also been told to try a low fodmap diet, which hasn’t worked.  |
| 17 | The pill was offered but I was trying for a baby  |
| 18 | Mefemanic acid - definitely spelt that wrong And the pill - MANY different versions  |
| 19 | I was offered a contraceptive pill to try and manage my pain, however this did not work and I felt more pain and discomfort. I also explained to my doctors that I was skeptical to take this contraceptive pill as my symptoms started around the same time that I first began taking a contraceptive pill for sexual protection a few years ago. I was not listened to, I felt as though my experience with 3 different types of contraceptive pills were disregarded and was encouraged to try another anyway. Additionally, I was encouraged to take Ibuprofen, an anti-inflammatory medication but I explained that I explicitly cannot take Ibuprofen due to other stomach problems but this was not taken seriously.  |
| 20 | I have concerns about the pain management offered such as the pill because it doesn’t deal with the underlying problem, just masks the pain away  |
| 21 | I am currently on a strong contraceptive pill to manage the pain and it has improved my life dramatically, the pain is no longer constant and I can do things now that I couldn’t before because of the pain, eg sex, concentrating when on my period etc  |
| 22 | I have been offered contraception, pain killers and anti-inflammatory pain meds. These do not help it’s like putting a band aid on a wound.  |
| 23 | I was given the progesterone only contraceptive pill. This never helped with my pain until they doubled my dose for 6 months to stop my periods. Long term use can cause problems.  |
| 24 | I am currently on millinette, a contraceptive pill, and it is doing well at masking my symptoms. When I do feel pain, I take naproxen. I worry about both of these medications effects on my mental health and also the health of my stomach, as naproxen can be quite damaging to the stomach lining.  |
| 25 | I have been on the pill since 16, masked my period symptoms until I was in agony, after surgery i take two to prevent periods, still get pain but not as bad Pain killer wise I’ve had pretty much every thing and it either doesn’t work or makes you exhausted or really dizzy/nauseas  |
| 26 | I am on the contraceptive pill (where I don’t take a break and don’t have a period at all) for my endo pains but I still do get them sometimes so the pill doesn’t help all the time.  |
| 27 | Frustratingly for myself contraceptive did not at all work for myself.  |
| 28 | I am currently on contraceptives which mean I no longer menstruate. I am concerned about this treatment because it increases the risk of other illnesses and I have also experienced side effects like weight gain.  |
| 29 | I have been offered contraceptives a lot however the effects they have on my mental health are simply not worth it. It was only mildly effective at managing the pain.  |
| 30 | Contraceptives. It can be effective and help with symptoms but again this seems to be used as a way out for drs who push and almost pressure us to use it so that the real help such as surgery doesn't need to be considered.  |
| 31 | Contraception, it worked to manage pain, but had a hugely negative effect on my mental health  |
| 32 | Yes - I am on two types of hormonal therapy (IUD and Orilissa) - it has me go from non-functional to reasonably okay but I still have a lot of pain, as well as many other unpleasant side effects (hot flashes, decreased bone density, chronic nausea)  |
| 33 | I have been offered and have used a range of medications. Mefenamic acid in early teens along with the contraceptive pill were the first interventions. I am now prescribed dihydrocodeine (which I cannot take, because I cannot function while taking them), and receive depo-provera injections every 3mths. I have tried mefenamic acid, cocodamol, naproxen, and my gynaecologist will not see me again unless I have a coil fitted. Even then, I will be referred to chronic pain clinic, rather then excise any more endometriosis.  |
|  | **Q5. Surgery can also be offered to manage and alleviate endometriosis pain. Have you been offered or experienced this form of treatment and do you feel like this was or would be an effective way to manage your pain?** **Do you have any concerns about this treatment?**  |
| 1 | I am still waiting for anything surgical. At this point, I am willing to give anything a go as nothing else has worked so far but I do know I will need have surgery to remove severe adhesions during a diagnostic laparoscopy, it is just a matter of when.  |
| 2 | I would certainly consider surgery, I haven’t done extensive research into it yet, but if I found it to be statistically effective and seemingly apt for myself - I would go ahead with it after consideration of the pros and cons.  |
| 3 | This is my likely pathway, and I feel this will be effective in the long run.  |
| 4 | I have had surgery but not to manage pain but to ‘clean up’.  |
| 5 | Surgery actually helped for a while but it’s not a permanent fix so does need to be repeated. Surgery carries it’s own risks so does concern me but I do feel like surgery is effective in helping with pain management for some time.  |
| 6 | Yes I have had surgery twice and feel the first surgery worsened my symptoms but my second with a different surgeon, helped massively. I feel surgery should only be carried out be specialist endometriosis specialists  |
| 7 | I was offered surgery to alleviate some of my symptoms but due to covid it got cancelled on the day, I am still waiting for it to be rebooked.  |
| 8 | Not been offered this but was discussed if no improvements, scared of surgery of any kind really, so would need to be the only option left really.  |
| 9 | I’ve had eight surgeries in the past 13 years. All had painful and debilitating side effects. Currently waiting for a hysterectomy date.  |
| 10 | I was not offered surgery due to my desire to eventually conceive, and the placement of the endometriosis was mainly centered around my right ovary - which they wanted to avoid.  |
| 11 | I’m on a waiting list for surgery. It’s been 4 months so far with no real idea of how long the wait will be. I feel surgery will help my situation 100% it’s just a matter of waiting. No concerns about it.  |
| 12 | Of course one has concerns because endo can come back even after surgery. I am waiting to see how my symptoms evolve but since my scans show very little endometriosis (mostly ligaments and adhesions) I was told to wait for surgery.  |
| 13 | I was not offered this treatment but I have concerns as friends have had scar tissue left after surgery that has also been painful and have had difficulties getting pregnant.  |
| 14 | Yes I've been offered surgery and have been on an urgent wait list for this since 2018 and still counting. I agreed to a total hysterectomy as I've also been diagnosed with Endometriosis's evil sister Adenomyosis. I also require the endometriosis to be removed from my outer bowel but as this was from an mri scan back in 2018 I may require more invasive surgery. Hysterectomy seems to be the favourite option of surgery offered for the treatment of endometriosis even although endometriosis present on other organs will continue to grow and spread until it is fully excised. As its on my bowel I will always now have endometriosis unless my bowel is removed  |
| 15 | I haven’t been offered surgery as my consultant didn’t want to do it  |
| 16 | I have been told that if my low fodmap diet doesn’t work (which it hasn’t) then I’ll be considered for a laparoscopy. I’m hoping that this will help, but am aware that it often does not rectify the problem.  |
| 17 | I had surgery which got rid of most of my pain  |
| 18 | I was extremely close to being offered the surgery but because my most recent period didn’t hurt as much as usual I wasn’t offered it. Still to this day I’m shocked at that reasoning  |
| 19 | I have been offered surgery but have been on the waiting list for a good few months (approx. 6 months). I have been asking for the surgery for a long time before I was offered it, as I researched that surgery is the only true way of diagnosing endometriosis. I feel like this will be a breakthrough in my diagnosis and feel like my pain and experience will finally be taken seriously. I don’t have any concerns about the treatment as I am more focused on - and longing for - answers.  |
| 20 | I have been offered surgery but was told that regardless of whether I have the surgery or not the end result is the same (pain management such as the pill) so they made me feel like surgery was pointless  |
| 21 | I was offered surgery if the pill didnt work out for me as more of a last resort, I would only do this if necessary  |
| 22 | I had a diagnostic laparoscopy by an inexperienced doctor which lead to ineffective treatment.  |
| 23 | I have had 2 surgeries. My concerns are misinformation. Many people will have ablation surgery which isnt great and can cause more problems. Excision surgery is the best! Too many surgeries can also cause issues.  |
| 24 | I am awaiting surgery in august. I hope it will be able to minimise the pain I experience enough for me to come off of the contraceptive pill. I do however worry that my pain is caused by adenomyosis which will not be treated effectively at surgery, so my experience of pain may continue.  |
| 25 | Surgery was the best thing I did, but had I not gone private I would have waited over a year to be seen let alone booked in for surgery Far too long to wait, if I couldn’t afford the private surgery my mental health would have had serious deterioration  |
| 26 | I haven’t been offered it yet but because I’ve never had a surgery before I would be hesitant to go forward with it  |
| 27 | I've had 3 larposcopys.. 1 major surgery Now Waiting radical surgery,full hystercotomy and removal of more endometriosis. Yes for short term pain relief these surgeries have worked for a maximum of 6 months.  |
| 28 | No. |
| 29 | I have been told this is an option in the future but it is not currently on offer.  |
| 30 | No haven't been offered doctors have suggested I am too young or its too invasive. I think this option is significantly better than just being pushed away with pain meds and contraception as the surgery helps to see how bad the endo is and remove some of it if necessary.  |
| 31 | No. |
| 32 | I am waiting to have surgery later this year and I am very optimistic but also terrified because it's surgery  |
| 33 | I was 35 before I was offered an exploratory laparoscopy. It was a day case it took 3wks to recover from , and the consultant spoke to me and debriefed me while I was still heavily sedated. No one stated endometriosis, only that ovary had been released from my bowel, and considerable amounts excised. Once recovered, I had 2yrs of low pain in part due to pregnancy which happened 3mths after the procedure. Even though breastfeeding heavy bleeding returned 6wks after baby was born. Now, at 38, I've twice considered visiting A&E for pain management, but the gp will not refer me back to gynaecology.  |
|  | **Q6. Whilst not as common as medication, alternative, non-medical self-management treatments such as acupuncture and cognitive behavioural therapy have more recently been offered to help manage the pain caused by endometriosis.****Have you been offered this form of pain management and do you think it was or would be an effective way to manage your pain?**  |
| 1 | Nothing like this has ever been offered to me. Apart from exercise and healthy eating, nothing holistic like acupuncture has been offered to me, though I have read up on pelvic floor physiotherapy and how it works for others with similar lower pelvic and lower back pain as I do and I would be willing to try.  |
| 2 | My pain is not currently severe, but I do already engage in yoga and meditation, which have helped with my PCOS - so I would continue with this, as research shows it helps for endometriosis management too. I would also consider acupuncture, CBT and Cupping therapy.  |
| 3 | Not been offered, it may help and I'd be willing to try it alongside traditional pain relief.  |
| 4 | None. |
| 5 | I have never been offered non medical therapies for my endometriosis pain management.  |
| 6 | No I have never been offered these options but would be open to trying them  |
| 7 | I've not been offered it but I would be willing to try it  |
| 8 | Not been offered this at all, don't think I would do it anyway, sounds like it would be like mind over matter, not real medicine.  |
| 9 | I’ve been having treatment on the nhs for endo for 13 years. I’ve never been offered cbt or acupuncture  |
| 10 | Yes, I have tried acupuncture and pelvic floor physiotherapy for my endometriosis. Though it was not immediately effective, it did help my overall understanding of my body and offered some different insight.  |
| 11 | I’ve not been offered, it could work for some.  |
| 12 | No but when I got diagnosed with endo I had been on cognitive behavioural therapy for about two years. About six months after the diagnosis, I started with Zoloft to help me manage intrusive thoughts - but therapy is key to wellbeing and I strongly believe in it  |
| 13 | I have not been offered these options in the past but I would certainly try all treatment avenues if pain resumed.  |
| 14 | I try to use alternative non medical treatments to deal with my pain, I was not offered cbt for pain management but sought out a pain management course recently and found it very useful. It should be offered as standard for all chronic pain individuals. I also use a tens machine and hot water bottle and recently went to my first reflexology appt.  |
| 15 | I haven’t been offered this, however I go for accupuncture and sports massage privately once a month and this is really effective in managing my pain  |
| 16 | I have not been offered this but would be willing to try any alternative methods that are backed by some evidence.  |
| 17 | No. |
| 18 | I’ve not been offered it but have been told to try acupuncture, have never done it though  |
| 19 | I have not been offered this sort of treatment but I also don’t feel it would be effective. To me, offering a mental health service for my chronic physical pain feels like a kick in the teeth. I want help, I want real treatment that will fix/stop my pain.  |
| 20 | No I have never been offered this and I’m not quite sure how it would help  |
| 21 | Not been offered  |
| 22 | I have been told to try CBT while I’m already in DBT for my mental health and they suggested my pain is just all in my head and it’s just anxiety.  |
| 23 | I haven’t been offered this.  |
| 24 | I have been offered CBT and undertaken it, but not for the purpose of pain management relating to endometriosis.  |
| 25 | Not been offered it, don’t know how I feel about it as haven’t tried it, at this point anything is worth a try  |
| 26 | No I haven’t been offered it  |
| 27 | I've never been offered these type of therapy, however I strongly feel they would not have effect.  |
| 28 | No. |
| 29 | I have been offered behavioural therapy which helped slightly however it did not make my pain any more manageable.  |
| 30 | No haven't been offered any of this.  |
| 31 | No i haven’t but would like the opportunity  |
| 32 | Have done some stuff on my own, nothing offered from a medical standpoint. My experience is that it takes more effort than it offers pain relief  |
| 33 | Haven't been offered anything.  |
|  | **Q7. Reduced quality of life and high levels of stress, anxiety, depression and emotional distress have been found to be associated with the pain caused by endometriosis.****Have you been affected psychologically by endometriosis and were you offered any psychological support? If yes, please explain how and what.****If you answered no to question above, are there any specific factors that have helped you to cope and manage the condition?** |
| 1 | Yes, more recently I have felt the psychological effects of possibly having endometriosis. I have feelings of guilt, self doubt, and even frustration with the quick deteriation of my health. I feel guilty that my partner has to see me in so much pain, see me bloated to the point that I cannot even eat or drink because of the nausea, having to need them around when the fatigue hits. This isn't the person I was when we met and now I come with this extra baggage. There is also the possibility that we may never have children due to the placement of my adhesions and the state of my pelvic floor and this weighs heavily on my mind. I personally don't feel the need to let the GP know about this impact as it doesn't effect how I am in myself overall, just on the bad days, and I have my own way of managing my thoughts on my health and my possible diagnosis. |
| 2 | It can be frustrating to manage the pain sometimes, especially with being on a long waiting list to be seen by a gynaecologist. I have been anxious at times, but I am quite good at managing my stress/anxiety, so my QoL hasn’t been impacted too much. I haven’t been offered any psychological support as of yet. Yoga, meditation, positive thinking, focussing on other things, resilience - knowing that I’ve dealt with other conditions in the past, and will also be able to manage this  |
| 3 | My life has come to a shuddering halt, which has caused me some distress. I've not been offered any support, but I've not felt I've needed it, else I would ask. Supportive partner, full sick pay  |
| 4 | No. |
| 5 | Suffered hugely with depression and the support was not great. I was offered anti-depressants and also was referred through to healthy minds, who then proceeded to tell me I didn’t really qualify for help because I seemed to be managing on my own. It was disheartening because I only reached out because I felt like I urgently needed the support and it was just dismissed and not taken seriously at all.  |
| 6 | Yes I have been effected physiologically with anxiety and depression but have never been offered any support  |
| 7 | I become very tired and the affects my mental health as I'm not able to do the things I like - this can make me feel really low and isolated at times.  |
| 8 | When the pain is bad for a long time I do feel depressed, but I haven't really talked to the GP about that part of how I feel. Nothing really - just being comfortable - taking some time off when I need to, making the most of good days.  |
| 9 | I have severe depression, severe anxiety and moderate chronic fatigue. I can’t manage a social life or relationships due to pain and exhaustion. I’ve lost friends due to the way my symptoms limit my life. I’ve been this was for more than half my life. My gp is aware but I’ve had zero support from them at all. Surgery helps short term but the endo comes back. Hormone treatments exacerbate my depression. I’ve been offered no support and no counselling by my GP.  |
| 10 | Yes, I was/am affected psychologically by endometriosis, but no I was not offered any psychological support. Understanding more about how endometriosis was affecting my body was helpful to me. By eventually getting more information from a new specialist, I was able to understand the triggers and causes of my pain.  |
| 11 | Yes. Anxiety. My dr referred me to a health and well being coach to help sort my diet and lifestyle.  |
| 12 | Not offered psychological support, already did therapy before the diagnosis. I have a diagnosed anxiety disorder with a strong obsessive component (which causes major distress, but does not qualify for ocd), which started with emetophobia - fear of vomiting. Hypocondria added up as I have been experiencing a variety of mysterious symptoms over the years, which culminated in chronic pain. Following the pain increase, my therapist at the beginning hypothesised depression - I had a tendency to complaint and self-victimization, so it made sense - and honestly apologized after I got diagnosed with endo Zoloft :) cognitive behavioural therapy lots of self love setting goals for my life and career yoga  |
| 13 | It was certainly distressing because I didn’t know if the symptoms would ever subside. It had a big impact on my sex life and my relationship during the peak of experiencing the worst symptoms. I was not offered any psychological support. Speaking to friends and family who’ve also got endometriosis and reading online forums and support groups.  |
| 14 | I have been affected greatly but this has been dismissed by my gp and it wasn't until I was literally feeling suicidal that I was referred to physiology which has approx 1 Yr wait list  |
| 15 | I have been affected by this, but take anti depressants now. A link between endometriosis and depression has not been made in my case  |
| 16 | I have definitely been affected psychologically both by the symptoms of endo itself, and the side effects of constantly taking contraceptive pills. I have made my GDP and gyno aware of these issues but have never been offered support. I sought out hypnotherapy myself to help manage my anxiety. My anxiety is considerably worse when I’m taking the contraceptive pill, but the hypnotherapy has helped massively with this problem. Otherwise I’ve not managed to find a solution to the fatigue, sickness and pain.  |
| 17 | No.Tried to just get on and forget about the pain  |
| 18 | I have anxiety and most of the time don’t go out because I fear I’ll have a pain and need to leave but feel I can’t leave the social situation because they don’t understand the pain. I was never given psychology help I stopped taking the pill which helped my mental health massively. Other than that I’ve just stayed focused on one week at a time  |
| 19 | Yes I have been affected psychologically - I have found it has heightened my anxiety and depression and even explained to my doctor that it has affected my quality of life. I feel as though I cannot enjoy my life fully as I am always waiting for it to flare up. I was not offered any psychological support. I found that I just have to accept my condition for what it is, and until I have my diagnosis and been given some effective treatment - I may not be able to live my life fully.  |
| 20 | I have stress anxiety and depression but they treated it as a separate issue No. |
| 21 | Not really, was seen to relatively quickly about it and got a diagnosis within months so I didnt suffer as much as most women who arent diagnosed for years Being on the pill helps with my emotions and pain  |
| 22 | Yes big only with seeing the third gynaecologist because they didn’t believe my pain. Hot water bottle and pain meds but it made my Fibro and migraines worse.  |
| 23 | Yes. I got anxiety and depression at points becaus no one believes your pain. I used to sit in my GP office talking about how I'd rather not be alive then experience the pain I do. No help was offered. Not particularly. I built up a big wall and I made myself become stronger.  |
| 24 | I often worry about my fertility. Sex can also be painful; wanting to avoid sex can be really difficult on my long term relationship. I was not offered any psychological support until I specifically asked for it.  |
| 25 | Yes, has been a serious cause of stress and I’ve had symptoms of depression. I haven’t been offered anything to help with this despite expressing concern  |
| 26 | I’m just scared about the future (ie. if I can have kids) but not that scared that I need counselling for it  |
| 27 | Massively effected, emotionally mentally to a depressed state, endometriosis has taken away my quality of life.. I suffer daily. Never once offered any support.  |
| 28 | Yes I have been affected psychologically but was not offered treatment. I have been affected because for multiple days in a month I will be unable to function properly due to the pain.  |
| 29 | Yes, it’s distressing not to be able to do the things my peers can do, and I have been offered some therapy however this was limited and I have since chosen to go private with therapy which has helped with the psychological effects of this condition massively  |
| 30 | Yes the actual pain and symptoms and the way it has been handled by drs has taken a significant toll on my mental health- depression, anxiety, stress, etc.  |
| 31 | Yes, i am on antidepressants  |
| 32 | Yes, I am stressed all the time about it. I have not been offered psychological support Not really, I would rather have adequate healthcare and then I wouldn't need psychological support  |
| 33 | Yes I've been affected psychologically, low mood, brain fog, chronic pain is debilitating physically and mentally. I've never been offered any psychological support, despite calling GP in tears with pain. Just a stronger pain medication. Not really, just TENS machine and understanding informal support.  |
|  | **Q8. Do you feel as though the psychological consequences of endometriosis that you may have experienced, affected your ability to cope and manage your pain effectively?** |
| 1 | Stress has always been a factor in making my symptoms worse and now with the frustration of having chronic fatigue, I find that I am less patient with others because I am more aware of my pain now than I have ever been.  |
| 2 | No, but it should also be taken under consideration that my pain is not severe.  |
| 3 | I'm not sure  |
| 4 | None. |
| 5 | Yes definitely. I just eventually didn’t speak about pain and acted as if it was the same and didn’t want to tell people when it got worse as I just felt it was pointless because it was brushed under the carpet. The psychological impact definitely prevented me asking for the correct medical care and pain management.  |
| 6 | I think this could be the case sometimes, when we are in more of a negative place psychologically you may be more focused on the pain  |
| 7 | It makes me feel like I am letting people down when I am not able to do things, when the pain makes me tired and I am having to rest lots it makes me feeling like I am making others miss out on things because I'm not able to do them, this really gets me down.  |
| 8 | I suppose it might have made me feel as though I could be feeling really down and then it just makes the pain feel worse and like I don't want to bother trying to do much, which makes you depressed. Bit of a vicious circle some days.  |
| 9 | Yes. The pain, the exhaustion and the heavy bleeding have meant I can’t have a social life or relationships. I chose not to have children because I felt I wouldn’t be able to cope. I’m suicidal as a result.  |
| 10 | Yes. My lack of understanding of the disease added to it as well, but I mainly experienced agoraphobia to a certain extent. I was constantly afraid of having an attack of pain if I left the house especially at work or in a social setting.  |
| 11 | Side effects of the drugs make it harder to take the medication. Side effects include low mood.  |
| 12 | No I think that other issues had a major impact in how I manage pain. However, knowing WHY you're in pain might have helped...  |
| 13 | Yes because feeling distressed, confused and uncertain was not a good basis to manage pain and other symptoms from.  |
| 14 | Yes most definitely. From the age of 13 until I was 26 when received my diagnosis (accidentally through a routine lap to remove a normal cyst that turned out to be an endometrioma) inwas medically gaslighted and told to get on with the pain that all women dealt with monthly. My education has been affected, my career is affected, how I manage my household and care for my family are affected. Psychologically I'm a mess at times and when the pain is present I have total brain fog and can't make decisions about what to eat never mind how to deal with the pain.  |
| 15 | Yes! When you’re struggling psychologically, everything just seems harder to deal with  |
| 16 | Yes. I constantly feel nauseous and I’m often worrying about my pain and sickness having an effect on my work as a self employed person. I then get very overwhelmed and exhausted, so tend to end up sleeping a lot instead of using alternative pain management methods.  |
| 17 | No. |
| 18 | I feel like the pain is all in my head sometimes which I hate so I try to convince myself it’s not there when it clearly is  |
| 19 | Yes, I feel helpless when I try to manage my pain. I feel overwhelmed and I can sit there for a while and just not know what to do. I feel like I have given up trying to manage my pain. I’ve noticed it has become part of my life and I am used to it, to the point where I don’t notice the mild discomfort anymore. I don’t think I even realise that a healthy person doesn’t have this constant pain.  |
| 20 | No, like I said above I always saw Endo and my mental health issues as two separate issues  |
| 21 | No. |
| 22 | Yes with the gaslighting from doctors.  |
| 23 | Yes, when I experience pain it's as if I feel defeated  |
| 24 | Stress can definitely impact my experience and regularity of pain; if I am worried about endometriosis, I often find I experience more flare ups.  |
| 25 | Yes, the more stressed I was the worse the pain was  |
| 26 | No I don’t think so  |
| 27 | Not having the correct pain relief has massively effected me psychologically. My confidence as been effected due to having to not been able to participate in activities that I once would.  |
| 28 | Yes, I also began to blame myself for not being able to handle the pain and attempted to simply "suck it up".  |
| 29 | Yes, if I’m in pain mentally, my physical pain gets so much worse.  |
| 30 | Yes, it gets difficult to maintain healthy eating and exercise that can help. It also gets to a point where you don't want to get out of bed or do anything which just adds to symptoms like fatigue and achiness.  |
| 31 | Yes and it would be hard to cope with physical pain whilst experiencing low moods and lack of energy  |
| 32 | Sometimes I can't be bothered to do yoga, it's easier to just take a bunch of advil strap on a heating pad and suffer through it. The emotional exhaustion of trying new things gets to me a lot  |
| 33 | Pain makes it more difficult to manage everyday tasks, it also prevents me from handling low level stress adequately. I am reclusive and rarely socialise due to heavy bleeding and pain.  |
|  | **Q9. Research suggested that women often report multiple trips to the doctors in which their symptoms are normalised, disregarded, delayed or incorrectly diagnosed before receiving a definite diagnosis. This may have a negative impact on their confidence towards treatment.****Have you experienced this and did it affect your trust in the healthcare professional and your ability to cope with and manage your pain?**  |
| 1 | This has been my experience for the last 15 years, by both men and women GPs, school nurses and even friends. It took until I became severely anaemic last year (after 14 years of issues) before my symptoms were believed and I was referred to gynaecology to find out more. I feel a lot of mistrust towards the health care system in general, simply because I have been told that my pain was in my head, that I must have a low pain threshold or that I was in pain because I was fat. I even had one consultant disregard any of my blood test results and my pain/symptoms and attempt to put me on a diabetic clinic list because I was overweight, I'm not diabetic and all it did was cause many years of disordered eating. The pain remained the same and I still had severe periods.  |
| 2 | Absolutely; I was sent to A&E in case it was appendicitis, the doctor basically disregarded my symptoms and barely checked anything (he should have done blood tests at the very least) - he just put it down to period issues or PCOS related. I then had to ring it GP many many times and express my frustration for them to realise that I know my body well enough and need to be taken seriously. I was then given lots of blood tests an ultrasound referral (for which there were also many many waiting lists), only for the radiologist to not follow GP request to scan whole abdomen and pelvis - she only scanned ovaries and uterus. I then wanted a private ultrasound, to ensure it was done properly, and for that I had to wait a couple of weeks for a gp referral. I have also been referred to a gynaecologist to check for endometriosis, as nothing significant enough showed up in the ultrasound and blood tests. But again, the gynaecologist appointment is 2 months away, until which I just have to carry on with the pain, each month as doctors can’t do anything else.  |
| 3 | I've been taken seriously by every doctor I have spoken with, and believe the medical decisions made have all been appropriate. However, having to speak with a different doctor every time does hamper this. I would like my doctors surgery to have someone who leads on this and menopause etc, ideally, but would be happier with a consistent doctor overseeing the management of my condition.  |
| 4 | I was diagnosed when I was 35! No one spotted anything before and the diagnosis was by accident.  |
| 5 | I was misdiagnosed with IBS from a young age. I was told that the pain was in my head sometimes and that nothing was wrong with me and that it was just a ‘bad period’ when in fact, it was much more than that so that caused me to loose trust in the doctors and my parents as I thought they weren’t listening to me and my concerns  |
| 6 | Yes and it has majorly impacted my trust in the health care system causing me to suffer in silence rather than seek help  |
| 7 | Yes I felt it was dismissed as period pains for a while, and the fact that my surgery has been cancelled following on from my diagnosis makes me feel that my health isn't important to others.  |
| 8 | It took a while before I got diagnosed, but I just kept going back and saying this definitely wasn't normal. I think the doctors were ok, it can take a few trips for anything to work out exactly what the problem is.  |
| 9 | Yes. My painful periods were normalised from the age of 11. From the first symptoms of endo at 22, it took me 12 years to get a diagnosis - I was variously told that the pain was “due to the way you walk”, was “just period pain” and - after diagnosis, that I should have a baby to fix it. I have no trust that anyone in the healthcare profession cares what I’m going through or cares about helping me. They want to tick a box and move on to the next patient.  |
| 10 | Yes to both questions. Before I was formally diagnosed, I explained to my (male) OBGYN that I was experiencing pain 3 out of 4 weeks of the month. He actually scoffed at me, and told me it was impossible that I was in pain that often and said birth control would help. It wasn't until I was urinating blood with blood clots with no infection detected 4 times in one year, and was experiencing bloody bowel movements that he decided to send me for further testing for endometriosis.  |
| 11 | Yes. At first mine was thought to be appendicitis. But I took myself to the A&E department of the women’s hospital and they were fantastic there. I probably experienced this years previous but I was never even thought of to have endometriosis. Just I have bad luck in having painful periods.  |
| 12 | Yes. I went through a time where I would not trust any healthcare professional. Even now, when I see a doctor, I try not to have expectations  |
| 13 | I was first diagnosed with a cervical ectropian. It was never really explained to me if this was separate to the endometriosis or not and I saw about 3 or 4 different consultants over a short period of time. After surgery I was able to go home without seeing a consultant but it then took a very long time (around two months) for the consultant to actually confirm the result of my surgery and I had to chase this up several times through my gp. This gap in communication, lack of consistency throughout my consultations and general ‘trial and error’ approach to my treatment made me feel mistrusting of the diagnosis process and subsequent treatment.  |
| 14 | Yes I have been gaslighted by GPS, gynaecologists, nurses, A&E. I have very little faith and trust in HCPs due to this.  |
| 15 | Yes! It took me 8 years to get a diagnosis. I feel as though I don’t have it in me to fight and advocate for myself anymore as it’s just so exhausting. Particularly as even though I have a diagnosis, drs still don’t fully understand it  |
| 16 | Yes, I have been attending the GP with endo symptoms for 9 years. It wasn’t until I came across the condition that I demanded a referral to a gynaecologist and they sent it. When I raised endo as a potential issue I was given the reply ‘I don’t know anything about that condition’ from the GP. Non specialist gynaecologists also seem to misunderstand the condition and it was only when I recently went for a private consultation that I was believed and was told it’s highly likely that I have the condition. I am now waiting for a investigative laparoscopy to be sure.  |
| 17 | Yes I went to the doctors multiple times over 10 years and was told it was just period pain  |
| 18 | Yes yes yes I have lost count the amount of times I went to the doctor about my pain and they just suggested the pill or pain killers or even nothing and just rushed me out. I hated it, reached points I would just bare with the pain bevause I didn’t want to go back for them to tell me the same thing and not help. I only managed to get referred to the hospital after a new woman doctor started at the surgery.  |
| 19 | Yes absolutely. I have been to the doctors many, many times and each time I’ve felt disregarded. After multiple tests for Colitis, crohns, PCOS, coeliacs disease, etc, and all tested negative. I suggest many times ‘could it be endometriosis?’ As I knew it was under researched and harder to diagnose. But my questions were always disregarded or not looked into. It took so long before someone listened to me and agreed that it could be, I think it was around 1.5 years. This really knocked my confidence in my doctors and it was really disheartening to be ignored, I felt like ‘why is no one listening to me?’ It was tiring and an awful experience really.  |
| 20 | Yes I went to the doctors from the age of 12 with bad period pains and it wasn’t until I was 18 that I was referred to a specialist  |
| 21 | I was lucky- I first reported my symptoms to a younger female GP who suspected it was endometriosis and referred me to a specialist gynaecologist immediately, so never had issues with delayed diagnosis. I know this is extremely rare though.  |
| 22 | Yes I have been trying to fight for the proper care since I was 10 and have been constantly gaslit and told my pain was normal and it told to take anti hestimine before having sex.  |
| 23 | Yes. It took me over 6 years to be diagnosed. Was misdiagnosed with hormonal issues, issues because my grandad died, slipped disks, hip impingement, nothing wrong and then hip dysplasia again.... I saw 5 physios, changed GP practise 5 times, visited 3 different hospitals. Saw drs both in Liverpool and Norwich because of uni. I now dont trust drs that when I broke my foot I refused to go to the GP for 3 weeks because I thought I was going to get fobbed off.  |
| 24 | Yes, I went to about 8 doctors before deciding to go private. It has significantly impacted my trust in healthcare staff. It has subsequently made me want to avoid going to the GP for any other health problem in fear of being dismissed.  |
| 25 | 1000000000000% this happened for nearly 2 years, was tested for crowns, diabetes, kidney problems, pregnancy, sit‘s, ibs, allergies you name it! And when I suggested endometriosis they felt my belly and said I don’t have it 😂  |
| 26 | Yes, multiple doctors put it down to period cramps or IBS (for which I’ve had tests done and I don’t have IBS) and just sent me on my way, which is so frustrating because I know my own body and I know my period cramps (when I had periods) are different to endo pains  |
| 27 | My goodness yes!!! It took numerous years and visits to my gp to get this addressed. It makes you feel as though you are making symptoms up,before you are finally referred to gynaecology.  |
| 28 | Yes, I have consulted multiple OBGYNs who dismissed my symptoms as a part of puberty.  |
| 29 | Yes, it has taken me 6 years to have someone take me seriously. This has affected my trust in the healthcare system however not significantly enough for me to avoid them.  |
| 30 | Yes this is all I have experienced. It definitely reduces confidence in your own feelings and makes getting help significantly difficult. Itakea you doubt drs and feel as though you are just a burden. I have totally lost faith in my own thoughts and feelings and feel genuinely terrified to try and speak to more drs.  |
| 31 | Yes it took a while for a diagnosis  |
| 32 | Specialists will be like "I see you're in pain every single day, my next appointment is in 4 months we can assess then if anything's changed and then discuss whether you're a good candidate for surgery at that time" no one gives a shit if you're not dying or trying to get pregnant  |
| 33 | Yes, and yes. I have had my symptoms minimised, and been sent away with more medication, with little regard for how it is affecting me mentally. I had to fight for nearly 20yrs to get an exploratory laparoscopy, and even afterwards, the results were minimised and no one has documented it as endometriosis.  |
|  | **Q10. Research has identified that women often fear to appear weak due to the stigma that surrounds endometriosis and the normalisation of women’s pain as something to be endured.****Do you feel like this has affected you and how has this affected the ways in which you sought help and managed your pain?** **Please explain your response.**  |
| 1 | Personally no. I have never felt stigmatised about being open about my issues. Frustrated and embarrassed that I experienced periods the way I do but not stigmatised, this could probably be due to having parents who were in the health care system themselves so periods were never a topic to avoid. It has never stopped me from seeking help. It may have taken a long time to be listened to but I was always firm in my experience, just was never believed.  |
| 2 | I know that there is a stigma, and my mum in fact often dismisses my problems - but I have become very immune to society’s stigmatisation of everything and trust that I know my body and I know what is ‘normal’ and what is not. Pain like what I am experiencing now is not normal and must be diagnosed so I can start to manage it and do what’s right for my body, despite what others might think.  |
| 3 | I have been aware of this type of chatter prior to seeking help, though that didn't delay me. It did make me more anxious than I might otherwise have been, and I have been unnecessarily worried that I wouldn't be taken seriously. I haven't experienced this but the advertisement of these findings could be a barrier to seeking help.  |
| 4 | No. |
| 5 | No I don’t feel like the stigma affects me but I don’t like how sometimes it interferes with day to day life but being told from a young age to just manage the pain because it’s normal made me feel like I was weak because surely something ‘normal’ wouldn’t hurt so much.. So in my head I would always be afraid to talk about it and ask for help in see I was told to be brave  |
| 6 | Yes, especially in the work place  |
| 7 | I feel my pain was dismissed at first until I got my diagnosis.  |
| 8 | You do get the feeling that women are seen as weaker in some ways, being a bit over sensitive, but I am a confident type of person - so I wouldn't take much notice of that, I don't feel weaker.  |
| 9 | I don’t understand this question  |
| 10 | Yes, because I did not want endometriosis to define me or my lifestyle - so the fear of appearing weak is most certainly present at times. I do find that it was hard to have friends and family completely understand what I was going through which made it frustrating in the beginning.  |
| 11 | N/A. |
| 12 | Discovering endo was frightening but empowering. I felt like everything made sense, and I am slowly learning how to talk about endometriosis with people and sharing my story - since then, I have discovered that some friends also have chronic illnesses but feel like they need to be silent about them. I'm no good at being silent  |
| 13 | I think I’ve been more embarrassed by my symptoms than been worried about seeming weak because of pain. However, there have definitely been moments when I have hidden my experience of pain, especially before my diagnosis when I wasn’t able to explain what the cause was.  |
| 14 | Yes I always try to appear strong, I've been so strong in appearance and downplayed my symptoms that I've been sent home from a&e with ruptured endometriomas. My labour pain was more manageable that endometriosis  |
| 15 | Yes! Being diagnosed with endo was such a fight and although I knew that my symptoms weren’t normal, I felt as though I couldn’t advocate for myself as drs kept dismissing me  |
| 16 | No. I know that people have thought me ‘weak’, or not believed the severity of my symptoms until they have seen it for themselves, particularly when I’ve been on my period as then my symptoms are quite extreme . I have tried to push through the pain before and been physically unable to, so I know that I’m not weak.  |
| 17 | Just had to get on with it as was told it was just normal period pain  |
| 18 | My current job is one where I walk around a shop all day picking orders so if the pain it bad I’m going to struggle. There was one day it was insane and I asked to leave early and they flat out ignored me (leaving early for things is super common at my work so any excuse would’ve worked but “period pain” didn’t). I subsequently had to walk out of work, drive home, get my mum and she had to call an ambulance. Sounds dramatic but she went to 111 first and they arranged the ambulance. I went back to work the next day and I said I walked out for a medical emergency and said an ambulance came to my house they then said I assume it wasn’t for you then he carried on with his form and left and I felt too scared to say that it was for me and I don’t know why  |
| 19 | Yes, I agree with this statement. My endometriosis has caused my such pain that I have had to call into work sick and miss days out - many times my manager has actually just put it down to ‘period cramps’ and I have been slandered. I’m aware that this condition isn’t as well known as other conditions but I have also been told things like ‘Everyone gets periods, take some pain killers and deal with it.’ It infuriates me every time. I am not supposed to feel like this! I will not just deal with it, I want help!  |
| 20 | There isn’t enough known about endo!  |
| 21 | Women are expected to suck it up more often and endure more pain, but with education about endometriosis improving people are now more sympathetic  |
| 22 | Yes I have been told to just get on it, weather it’s just take meds to try and help the pain, A&E not helping me or being told to drink wine  |
| 23 | Yes. No one realy knows endo do alot of the time I dont bring it up. But I have a high pain threshold so I dont show pain unless it's bad. Drs often wont believe you of you hide it. Because I'm so strong and hide my pain when I visited my GP I over exaggerated everything  |
| 24 | I do not feel weak for having endometriosis but I do not like to complain about my pain because people do not take me seriously  |
| 25 | I think it has affected the time it took to seek diagnosis however I have a very aggressive attitude towards anyone that tells me my pain is less than it is or makes hypochondriac comments etc because of the rage endo causes from such stigma! I prefer to educate people rather than let them put me down  |
| 26 | No I don’t think so  |
| 27 | Yes this condition can make you feel weak in the eye of a GP. It's demoralising to have to seek many different GPS to get the help you so know you need. I'm speaking years of visits! Honestly wrong that you can be dismissed because this is simply period pain in the eyes of some. I've lost confidence in doctors due to this embarrassment of being missunderstood even when it comes to other ailments.  |
| 28 | Yes, I have been treated like the pain is not as severe as I make it out to be and that I am simply complaining and weak. This has affected my ability to speak about it. I have particularly experienced this from my family who gives me useless advice like asking me to exercise more or telling me I will outgrow it.  |
| 29 | I often had my pains dismissed as puberty etc, so I felt quite weak until I was told there was a possibility of endometriosis. Quite often I would just grin and bear it.  |
| 30 | Yes- it's often seen as just a bad period and nothing major so when you need help you feel like you're just creating an issue that's not there or like it's not valid.  |
| 31 | N/A. |
| 32 | I wish it was an easier thing to talk about so I could explain missing so much work  |
| 33 | Self efficacy affected. Concerns about committing to things because unsure if endometriosis will hamper plans.  |
|  | **Q11. How has the social norm of menstruation, being seen as something private and to be hidden, impacted upon how you manage and cope with your pain?** |
| 1 | If has not impacted how I manage my pain at all. I am quite open with my experiences and I'd rather people know that I get pain and fatigue.  |
| 2 | I ignore such damaging social norms, and speak openly about it when needed. I can cope with my pain, but I ensure that I don’t normalise it as it is not normal and should not be treated dismissively.  |
| 3 | It hasn't  |
| 4 | It hasn't  |
| 5 | Sometimes prevented me from asking about pain relief because it made me feel weak to ask for it and  |
| 6 | It has caused me to hide my symptoms sometimes I even feel as though I can’t even discuss the condition  |
| 7 | I have days where I can't get out of bed due to my periods, I have learnt to be more open about my pain and my periods but I do feel at times it can still be a bit of a taboo subject and people don't want to talk about or hear about them.  |
| 8 | It's one of the last things you really want to talk about, I am quite private, I try to put a brave face on it. So I think it has stopped me from reacting in the beginning, but not so much now.  |
| 9 | Yes. It’s hard to explain absence from work or a need to take breaks when these things are due to heavy bleeding and extreme pain. My managers have all been male and all told me I was exaggerating  |
| 10 | Honestly, I became way too exhausted trying to hide my pain or what I was going through and I completely disregarded any social norms eventually. Endometriosis is a huge part of my life and has a massive impact on me. The more I talked about it with friends and family, the better their understanding became.  |
| 11 | It’s something I keep to myself. If I’m having an off day with medication I may mention it but otherwise I don’t share.  |
| 12 | I have always been very open about menstruation and as I grew conscious of the stigma and patriarchal norms surrounding them I became more and more vocal about the issues that AFAB people can experience. I used to be in pain for about three weeks before being able to get my period and would tell everybody around me. No shame.  |
| 13 | I’ve probably shielded male family members and friends more-so from my symptoms as a result and I’ve not discussed it with them as much.  |
| 14 | It's hard to communicate with some GPS as they down play endometriosis as just period pain especially some of the older male doctors. When flare ups occur in work and only male managers are available it increases my anxiety as I don't find them approachable. I find the topic hard to talk about with my dad but I'm getting there. Sometimes I just say I'm having a flare up and leave it at that  |
| 15 | No as I’ve had to advocate for myself I’m getting a diagnosis from the age of 13 so it’s very much normal for me  |
| 16 | I feel that this has impacted on receiving my diagnosis, particularly when speaking to male GPs, but I do not feel that it has impacted my personal pain management (other than having limited available options). I actively try to promote the normalisation of period transparency, especially amongst my male family members, friends and colleagues.  |
| 17 | Work not believing that I couldn’t stand all day (worked in a salon at the time) saying it was just “my time of the month) boss annoyed I had to go home to change my clothes  |
| 18 | I think everyone learns pretty quick so keep it to yourself  |
| 19 | Menstruation is still such a taboo topic, and still feels embarrassing to talk about. Especially when I have to call in sick to work (and even more so when I have to speak to a male manager), I feel embarrassed. Even though it is absolutely completely normal, periods are still a taboo topic. Even when talking to a doctor, I feel like it’s something too private to talk about openly. I must stress, I have no problem talking about - but it is people’s and society’s reactions to the topic that makes me feel as though I cannot say anything. Almost as if, it is a women’s issue that you must deal with quietly and alone.  |
| 20 | I was too afraid to tell teachers at school how I was feeling when I had bad period pain  |
| 21 | My worst ever episode with endometriosis, while on my period, was handled by two male friends who didnt care about my period, only about getting me help and doing everything they could to help alleviate the pain. This experience has left me not really caring what people think/ignoring people’s squeamishness about periods, so I talk about it openly and freely. This has certainly helped because it means people are more open to helping me when I’m in pain generally.  |
| 22 | Yes because of the stigma it is to have periods and how normalised period pain is when it is not actually normal and the pain can’t be that bad...it’s another way women are oppressed.  |
| 23 | I've always been quite open so it's not affected me  |
| 24 | I do not see menstruation as something to be hidden so this does not affect me  |
| 25 | Hasn’t really effected me as you get to a point where you don’t care what any one thinks you just want to know what is wrong and how to fix it  |
| 26 | I often cope with my pain more privately, so I don’t outwardly express I’m having these pains when I’m in public  |
| 27 | I'm housebound when I'm in my worst pain,so this does not effect me.  |
| 28 | When I was younger I felt ashamed to tell the people around me that the reason I was unwell and passing out constantly was due to period cramps.  |
| 29 | Not at all, I’ve always been quite open about my menstruation and the effects of it.  |
| 30 | I for a long time just ignored how bad my symptoms were and dismissed them as normal. I also when things did get terrible not want to talk about it or not know how to. It had also impacted how I get help as it can be difficult to discuss symptoms/feelings with drs as you feel embarrassed for being open about them.  |
| 31 | I talk about it with my female friends but not at work and don’t put it down as a condition on medical forms at work due to embarrassment  |
| 32 | Lie to acquaintances and co-workers to get out of things frequently when I'm in too much pain to attend  |
| 33 | It feels like I should stop complaining and just get on with it that is what stigma around menstrual pain has done.  |
|  | **Q12. Do you have support from those around you such as friends or family with coping and managing your condition, and do you think that this is or would be helpful in encouraging effective pain management?**  |
| 1 | I have a really good support system in my partner and my family. They understand my limits and I think they would welcome any kind of relief offered to me, as well as continuing to support me on the bad pain days  |
| 2 | Friends are supportive, definitely - it helps to know that there are people who care and understand and will know if I need time to manage my pain if it is heightened sometimes. With people that I know do not understand, I don’t waste my mental effort trying to explain it to them.  |
| 3 | I do have support from family and my partner as well as my colleagues, who have all been really helpful.  |
| 4 | I do not have pain as I train a lot!  |
| 5 | I have good support but feel they’re not educated enough on endometriosis and that it would be more effective when they know more about it so they can help and encourage those of us who suffer with mental health at the same time, to seek help when we don’t feel like it  |
| 6 | I don’t unfortunately but yes I think it would be helpful  |
| 7 | My family support me lots but I do live alone so I mostly cope on my own when it comes to managing my symptoms. I have a period box with the pads I use, my heat pads and hot water bottles and my pain killers. I also have medication to help with constipation as the endo tissue is spreading and when I'm having a flare up this affects my bowel movements also.  |
| 8 | Yes it is really helpful when people are caring towards you, and understanding when I just can't do what was planned,  |
| 9 | I have no support. My family are unsupportive and after 24 years of this, my friends are sick of hearing about it.  |
| 10 | Yes, I do have support and to an extent it does help. The more people know about it, the more they can share that knowledge with others who may be suffering silently.  |
| 11 | Yes but I don’t feel like they can help in pain management.  |
| 12 | Not really - since I am know as the the one with hypocondria, people around me tend to minimize or think I complain too much. It would be helpful but impossible. Sometimes even my boyfriend suggests activities which might make me sick or even more in pain.  |
| 13 | I would have their support but don’t need it at the moment as my symptoms have subsided. But it was definitely helpful when I was having hospital appointments, surgery and through recovery to have the support of family and friends. It was useful for me to talk to friends who were experiencing similar symptoms too.  |
| 14 | Yes and no, sometimes people close to me get sick of the unpredictability of my social plans, needing help and support at last min or cancelling plans. But if definitely helps the more support I receive  |
| 15 | Yes, it has been helpful  |
| 16 | Yes I have good support from my friends and family, and they do as much as they can. Ultimately there are few reliable pain management techniques for endometriosis so there is only a limited amount that anyone can do, myself included.  |
| 17 | No, they didn’t really believe me either  |
| 18 | My family are super understanding of the pain and will help me with whatever. Some friends not so much and I’ve lost friends because they think I’m just lying everytime I say I can’t because pain etc  |
| 19 | Yes I do have support with my pain, but so many people don’t understand the condition and truly don’t understand the extent of my pain.  |
| 20 | Yes my family and friends are supportive  |
| 21 | Yes- plenty of support from family and friends, which helps a lot  |
| 22 | Yes my partner and my partners family are extremely supportive and do what they can to help me with my pain.  |
| 23 | Yes. My sister is supportive which is good. It helps to talk about the pain I feel  |
| 24 | I don’t think familial support would affect my pain management.  |
| 25 | Yes and no. I have support but sometimes people don’t know what to say when I complain about discomfort and pain which is very depressing as you’re often ignored! If family and friends were educated on effective methods and responses then yes but having people constantly tell you that you just need to go veggie or gluten free is very unhelpful, basically blamed for my pain on a daily basis  |
| 26 | Yes I do, my family understand and want me to get this sorted as much as I do which is helpful  |
| 27 | I have an amazing friend and daughter who help me through my worst days.. Unfortunately they cannot help with pain,I rely heavily on pain medication, however they are amazing support and they do help with day to day tasks. |
| 28 | I find my friends to be helpful but not my family - they have dismissed the condition and relate it to their own experiences with menstruation and how they have handled their own pain. It would be helpful if people did not dismiss or diminish my experience with pain so I myself do not as well.  |
| 29 | I do, my partner is a lifesaver and has helped me massively with things I can’t do due to the pain.  |
| 30 | Yes I have received more support from my boyfriend and other girls with endo than anywhere else.  |
| 31 | Yes , it can be helpful as they can do heat pads and get pain relief when i can’t move  |
| 32 | Yes, my partner is very supportive  |
| 33 | I have support from friends and family.  |
|  | **Q13. Are there any factors you feel have impacted on the care and treatment you have received? For example, your job role or income?**  |
| 1 | No. |
| 2 | Not really, just the stigma of young women with abdominal issues - blaming it on period cramps or just general dismissal.  |
| 3 | No. |
| 4 | Dunno. |
| 5 | Age. I think that because I was so young at diagnosis it wasn’t taken seriously and so the care and treatment was almost brushed off and not taken as seriously because I was always told ‘you’re young and your body needs to settle itself down’ it was always pushed as a young girl unable to deal with her period pains  |
| 6 | I feel that if I had a job with private healthcare I may have been treated better.  |
| 7 | I have a diagnosis of autism which until recently was misdiagnosed as adult ADHD, I feel this impacted how seriously I was taken and people's perception of my capacity.  |
| 8 | I don't think so but I can imagine in a more extreme circumstance it might make a difference - or feel like it does.  |
| 9 | N/A. |
| 10 | Not in particular, no. In Canada I have access to a lot of different procedures and treatment options. I also work for the federal government and have great benefits. I am fortunate in this way.  |
| 11 | My job wasn’t supportive whilst I was getting diagnosed.  |
| 12 | I am privileged because I could pay for private healthcare. so yes, huge impact. Also, I was able to research information in a foreign language too (English - way more resources than Italian) and read some research  |
| 13 | No. |
| 14 | Yes, if I was financially well off I would go private for treatment but can not afford this therefore I'm in the hands of the NHS and now covid delays  |
| 15 | The best endometriosis specialists are private but I am unable to see a consultant privately as I can’t afford to.  |
| 16 | Having a larger income would have enabled me to seek private care many years ago. I am still unable to afford private surgery so will likely need to wait another 2 years minimum to get to that stage. The NHS is not competent in the management and diagnosis of women with endometriosis in the UK.  |
| 17 | The job I was at when I had my operation were annoyed I had time off for my operation so I went back a week early  |
| 18 | N/A. |
| 19 | Honestly, I would love to see a specialist to be able to get treatment quicker, and talk to someone who actually understands my pain. But my income is too low to be able to afford anything like that. I also work in retail alongside being a student, and retail is not a very caring sector in my opinion. So I find that my bosses and managers are not very concerned about my well-being, more so just about if a shift can be covered.  |
| 20 | I almost lost my job because I was having so much time off with bad period pains  |
| 21 | As it is increasingly difficult for me to see the nurse/GP about getting repeat prescriptions for the pill I have started buying my prescription from the pharmacy, which I wouldnt be able to do if I was on a lower wage  |
| 22 | I have other medical conditions which can impact the endometriosis pain as well as having severe mental health issues. Income is an issue too because I don’t work (I’m a student) I can’t afford to go private to get proper care.  |
| 23 | Being a young girl, they try to blame it on hormones or say it's normal. Being a woman means you just dont get listened to as much.  |
| 24 | I think my age has significantly impacted how seriously I have been taken by doctors. It was not until I was over 21 and was confident enough to advocate for myself that further investigation was agreed by my GP  |
| 25 | Nearly lost my job at sainsburys as I had so much sick leave while trying to get a diagnosis. Was being given antibiotics for kidney infections that I didn’t have who CG impacted my immune system and led to hospitalisation over and over again! This added to the stress which added to the pain. My current boss is okay about it but makes comments about how I should manage my condition when she knows nothing about it and tells me “she has bad periods too” which makes me want to slap her  |
| 26 | No. |
| 27 | N/A. |
| 28 | As a woman of East Asian descent there is additional stigma in my community regarding women and menstruation. We are also expected to be compliant and non vocal. These factors have contributed to people not taking my concerns seriously.  |
| 29 | The lack of sick pay at my job has meant that I often push myself too far which makes the pain worse. But if I didn’t have a job my income would be nil so I’ve had to push through. This has often meant that a lot of people have underestimated my pain and I was often dismissed  |
| 30 | N/A. |
| 31 | N/A/ |
| 32 | I have a medical PhD and know how to speak doctor so it made them take me seriously. I still feel like I got poor care so I can't even imagine what someone without this advantage would have faced  |
| 33 | No. |
|  | **Q14. How would you define the area that you live in e.g. urban, deprived, rural, affluent and do you feel it has an effect on any aspect of your treatment or its availability?**  |
| 1 | I live in an urban environment and I come from a rural village. I have found that I have more access to health care in terms of GP availability but the barriers I have faced have been the same in both urban and rural areas.  |
| 2 | Small city - slightly deprived, but not massively - affluent areas are present. There is definitely a clear difference between the care I have received in this small city, compared to when I was living in a more urban and larger city. This small city has many waiting lists, low availability and lower quality of care - I understand that covid has impacted this further, but there has always been a lower quality of care at a much slower pace than the larger city.  |
| 3 | Affluent, rural area. Needing to go to local rather than major city hospital means there are fewer clinics and I think this has slowed down the process.  |
| 4 | Urban |
| 5 | City. lots of treatments available but long waiting lists for referrals  |
| 6 | Semi rural, I think this affects the facilities that are available to me  |
| 7 | Urban and deprived, I feel the lack of funding in my area and the NHS has affected my treatment and the speed in which it has been carried out  |
| 8 | semi rural, neither affluent or deprived (maybe aspirational), don't think it has made much difference  |
| 9 | Sadly my treatment has probably been better than most. I live in London and can afford to pay privately for counselling. I know access to gynaecology services is much worse outside of London. |
| 10 | I believe my answer above is relevant here as well.  |
| 11 | Busy city so the delay in getting appointments is long.  |
| 12 | I live in a small town but well connected with major cities. I also live in the north of Italy where the vast majority of endo professionals are based (as opposed to south Italy - so many people travel from Sicily to Verona to see their ob gyn).  |
| 13 | Urban area. I found it very easy to attend appointments as I lived close to the hospital. I don’t feel that this had a negative effect.  |
| 14 | It's urban and deprived, my closest hospitals a&e are closed at present due to covid I think!?! But normally would have run on a 9-5 opening. I have to travel 20 miles to my closest fully operational hospital for endometriosis treatment and the gynae there told me only himself and another doctor in NI can operate on me. I asked to go to the mainland for treatment and he said I can't.  |
| 15 | No. |
| 16 | Rural. Yes I do feel that it has delayed diagnosis. There are limited hospitals and medical centres nearby, and limited availabilities for appointments etc.  |
| 17 | Urban. |
| 18 | I live in a nice town which is fairly big. I don’t think the area has an impact on any aspect of my treatment or availability as I could’ve been referred to a hospital years ago but was only referred when someone took me seriously. I think it’s the people not the area  |
| 19 | I live in a more deprived area, and I feel the standard of the GPs and doctors are reflective of the area I live in. They are sub-par. I have always had a disappointing experience with my GP surgery through many other issues.  |
| 20 | Rural, definitely less support available than bigger cities  |
| 21 | I live in a major city, which helps as there are more resources I can access than living in the countryside  |
| 22 | Urban/deprived. It affects it because there is a lack of treatment options and qualified staff in endometriosis as well as lack of availability  |
| 23 | I live in a city within a deprived area I guess. It doesn't really have an effect tbh unless the drs are bias.  |
| 24 | I have lived in various areas in recent years and the care I have received in all of them has been below the standards I would expect. I have lived in an Oxfordshire village, a university city/ student area, and now live in a run down urban area.  |
| 25 | Urban, only 2 endo specialists in the entire of Wales! Thousands of patients... so there’s basically no availability of treatment and you get left for years suffering  |
| 26 | I live in kind of an affluent town as it’s famous for horse racing but I don’t think this has really affected the treatment I’ve received  |
| 27 | Rural I have to travel 52 miles to my gynaecologist  |
| 28 | N/A. |
| 29 | I used to live in a rural area and I was often dismissed, but as soon as I came up to an urban area, I was taken seriously, however the waiting lists are very long.  |
| 30 | Urban- living in London has made it difficult as the NHS is so stretched in the area.  |
| 31 | Urban |
| 32 | Urban - many doctors, although all still have a long long waiting list. Still probably better off than in a more rural area  |
| 33 | Rural. It definitely affected treatment. The waiting tome was so long to be seen by gynaecology and on one particular day, I waited in excess of 2hrs for my appointment time, in tears because I wanted to leave but knew I couldn't as I'd waited so long. The nursing staff stated the consultant was drafted from NHS England to tackle NHS Scotland waiting lists, and not familiar with the computer system. I was a shell by the time I was seem, and unable to articulate my thoughts. It was extremely poor. I am hoping that private health cover will take my condition seriously as I cannot go through the process again, even if the GP does eventually agree to refer me back.  |
|  | **Q15. Do you feel there are any treatments or pain management options that have not been offered to you but you feel could be of some benefit?**  |
| 1 | Anything other than OTC medication or hormonal contraception. I have not received any medical treatment outside of these two options and I feel that perhaps expanding these options would give me some benefits.  |
| 2 | I am still in the early stages prior to diagnosis, so there haven’t been any options offered properly yet. I’m not sure of any management options that ease the pain of endometriosis, and will look into it properly after a diagnosis as I’m sure the doctors will not provide sufficient information.  |
| 3 | Not as far as I'm aware - I assume hormonal treatments will only be offered once diagnosis is obtained, and I'll give them some thought at that point.  |
| 4 | You can say I self-medicate by training.  |
| 5 | Definitely a hysterectomy but I’m considered too young to make that decision about my own body and my own life. Even though living with this condition and suffering with the mental health too, affects more than just my body. It affects EVERYTHING  |
| 6 | Acupuncture Tens machine  |
| 7 | A hysterectomy would benefit my health but this has been refused due to my age - I have no desire to have any more children and I have had my tubes tied due to this but yet it is felt that I shouldn't have it.  |
| 8 | Now the options have really been discussed more, I suppose it improved alot with a proper diagnosis.  |
| 9 | CBT. Acupuncture. Help to manage the fatigue. Should have been offered a hysterectomy sooner.  |
| 10 | At this time, no. But perhaps that's because I'm unaware of all of the options that exist.  |
| 11 | Maybe. I haven’t been offered some non-medicinal.  |
| 12 | surgery  |
| 13 | I was experiencing what I felt was nerve-related pain at the peak of my symptoms. Normal pain-killer medication didn’t help at all (paracetamol/ ibuprofen). Heat application and breathing/ relaxation techniques seemed to be the only things that would ease the pain but this was not formally suggested to me.  |
| 14 | Yes there is a pain clinic in the Belfast Trust that I have never been referred to. Even though I'm from a different hospital trust I should be referred here as its the only pain clinic in NI. I would benefit from the specialist advice I believe.  |
| 15 | No. |
| 16 | Laparoscopy and/or a total hysterectomy. Even that does not always solve the problem though. As far as I’m aware there is no treatment that works for every case, and definitely no cure.  |
| 17 | No. |
| 18 | I think I should’ve been the one to choose if I want the laparoscopy not them at the point I was at.  |
| 19 | Not that I am aware of, I am not sure of what else there is that could help me.  |
| 20 | Not sure  |
| 21 | Before I was on the pill/if I wasn’t able to take the pill, I would want stronger pain medication for really bad days  |
| 22 | I don’t know. |
| 23 | Pain killers, pain management, pelvic floor physio, physio, therapy.  |
| 24 | Pelvic floor therapy  |
| 25 | No, the only treatment I have not been offered is Lupron and orlissa (if that’s the right name) and I don’t want either! Only 50% chance of working, side effects are just as bad as endo and often it ruins your fertility - no thanks  |
| 26 | I would like to be offered the surgery even if I am nervous about it, I would just like to have a formal diagnosis  |
| 27 | There's not many options at all available of which I know.  |
| 28 | N/A. |
| 29 | Not that I’m aware of.  |
| 30 | N/A. |
| 31 | No. |
| 32 | Anti-nausea medication that is non-drowsy, better pain medication  |
| 33 | Laparoscopy, dietetic advice, autoimmune testing. Something is wrong, there are more options not being offered.  |
|  | **Q16. Is there anything you would like to add that hasn’t been covered within the questionnaire?** |
| 1 | N/A. |
| 2 | N/A. |
| 3 | I feel there is a significant focus on endometriosis and fertility, whereas my major concerns have been physical mobility, eating and digestion, and pain management. I'd appreciate more balance and a greater reflection of a wider range of experiences in discussions about this disease.  |
| 4 | Training is key. I used to have lots of pain but now I don’t have any at all. I do 600 sit ups five times a week and do crossfit six times a week. A strong core makes all the difference.  |
| 5 | How endometriosis affects relationships, friendships, jobs and how it affects our ability to be parents during bad flare ups/surgeries/hospitalisation. Endometriosis doesn’t just affect the person suffering it affects their loved ones too.  |
| 6 | N/A. |
| 7 | N/A. |
| 8 | No. |
| 9 | N/A.  |
| 10 | Not at this time. |
| 11 | I would say it’s a lonely disease. No one understands it fully unless they themselves have it.  |
| 12 | no. thank you for your work.  |
| 13 | No. |
| 14 | N/A. |
| 15 | I was told that my consultant doesn’t want to do surgery but as my symptoms “look and sound like endometriosis, we’ll call it that” so, I have no idea where my endometriosis tissue is, how that may affect me in the future etc. So that’s scary!  |
| 16 | N/A. |
| 17 | No. |
| 18 | N/A. |
| 19 | No. |
| 20 | No but thank you for letting me participate and good luck!  |
| 21 | No. |
| 22 | N/A. |
| 23 | N/A. |
| 24 | N/A. |
| 25 | There needs to be further education in school about this And universities and work places need to understand that this is a life long physical disability and we shouldn’t be treated like hypochondriacs and we shouldn’t be made to feel like there is nothing wrong because we look “fine”  |
| 26 | No. |
| 27 | I feel that GPS should be offered more education for the condition, its beyond unreal that a patient should have to wait years upon years before being referred.  |
| 28 | N/A. |
| 29 | Nope :)  |
| 30 | I am not even fully aware of what I could access to help me due to the way in which drs have reacted to my asking for help.  |
| 31 | N/A. |
| 32 | N/A. |
| 33 | I feel that professionals should stop telling women to have babies to stop the pain of endometriosis. I've done it three times, the pain reduction is short lived, and when the pain returns, it returns worse. Reproduction is not the answer.  |