Medically complex women and abortion care

Background

One in three women will have an abortion in her lifetime. Abortion is a key part of women's reproductive healthcare and will nearly always be clinically safer than carrying a pregnancy to term. Abortion is a necessary back-up when contraception has failed or not been used effectively, enabling women to make decisions about the timing and size of their families. Women may also end planned pregnancies when a foetal anomaly is diagnosed, or when the context in which she hoped to have her baby changes, for example as a result of a relationship breakdown, or if she or an existing child becomes ill.

Abortion in the UK, with the exception of Northern Ireland, is governed by the 1967 Abortion Act. This does not provide for abortion on demand: rather it enables 2 doctors to authorise a procedure when they determine in good faith that she meets one of grounds laid out in the Act. The majority of abortions in the UK are carried out under Ground C, which stipulates that the abortion will be lawful if the pregnancy is less than 24 weeks gestation and that a woman's mental or physical health would be at risk were it continued. Any abortion outside of the Act carries a penalty of life imprisonment for both the woman and those assisting her under the 1861 Offences Against the Person Act. This means there is threat of prosecution attached to healthcare professionals offering abortion services which does not apply to any other medical procedure, and which can deter doctors from entering this vital field of women's healthcare.

Around 2/3 of abortions today are carried out in the not-for-profit independent sector, under contract to the NHS. The ongoing shift towards provision outside an NHS setting has largely benefited both women and NHS budgets, as the sector is able to provide high quality, woman-centred care in a cost effective manner. The independent sector is able to recruit and train doctors to provide abortions up to the legal limit of 24 weeks; however it cannot carry out all abortions. Many women with co-morbidities, such as uncontrolled epilepsy, diabetes, heart conditions or cancer, cannot be treated in a stand-alone community clinic, but must be managed within a hospital setting where there is swift access to backup care and specific clinical expertise in the event of an emergency. As the number of younger women with co-morbidities increases at a population level this is reflected in the pregnant population, both among those continuing and those ending pregnancies.

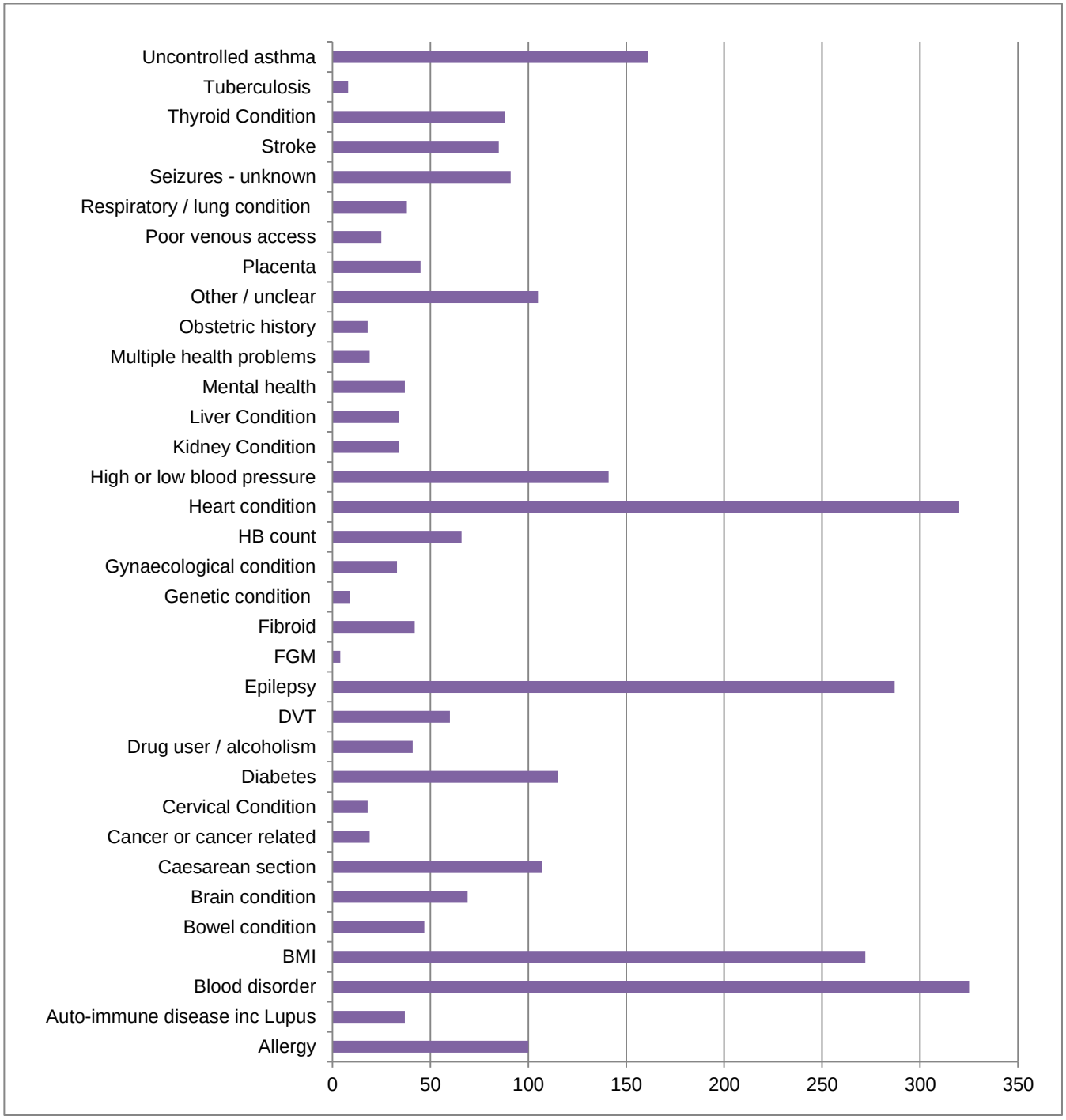
Women with co-morbidities who cannot be cared for in the independent sector can end up waiting for long periods with a pregnancy that is a risk to their health until an appointment within an NHS setting can be found. As NHS hospital provision becomes increasingly limited the further a pregnancy advances, **bpas routinely sees women who have been left with no option but to continue a pregnancy that they do not want and which poses a risk to their health.**

Key points from this briefing:

- Women with medical complexities need access to high quality specialist contraceptive services to help them avoid and plan pregnancy
- A nationwide pathway to ensure access to abortion services up to 24 weeks should be commissioned for women with medical complexities
- The stigmatising threat of criminal prosecution for abortion should be removed for all healthcare professionals providing this service and abortion care regulated in the same way as other women's healthcare procedures

Who are medically complex women?

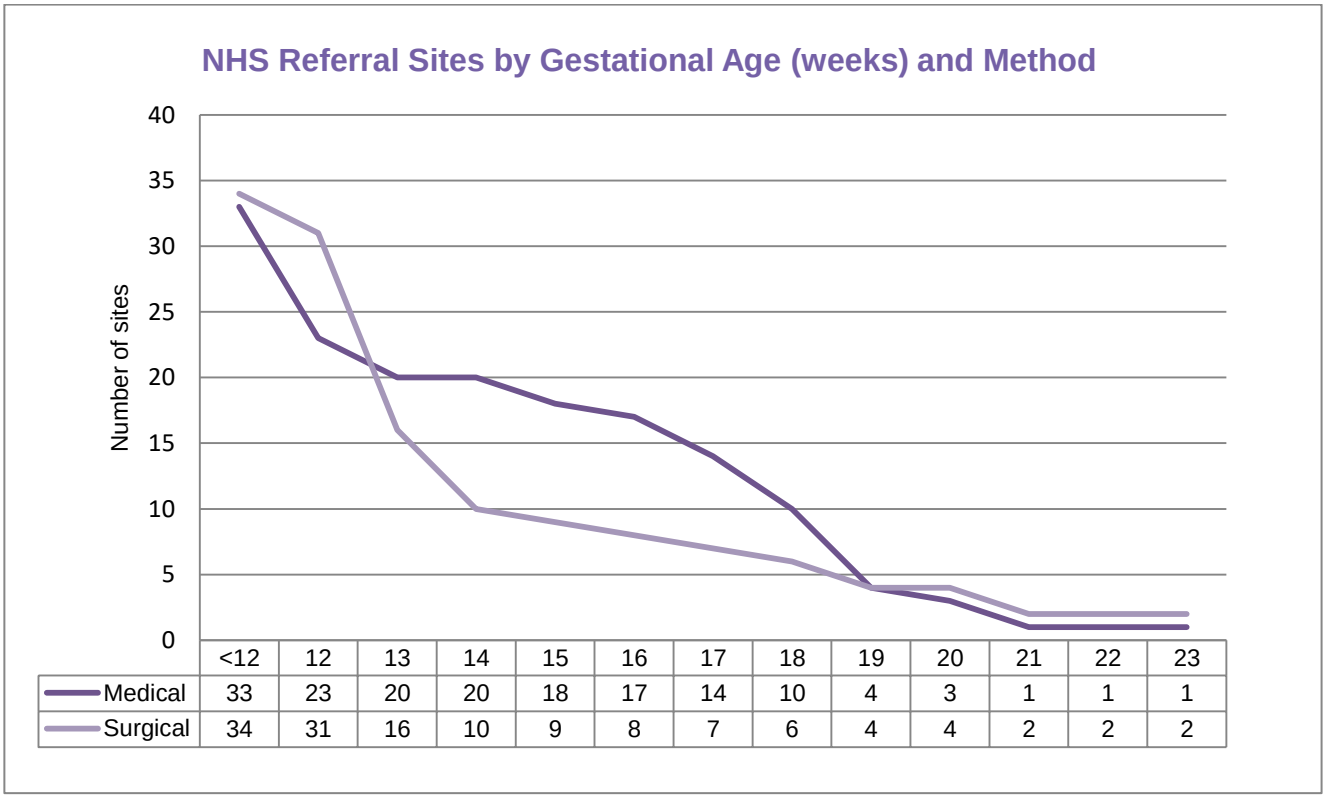
In 2007, in response to an increasing number of women who were clinically unsuitable for treatment by us, bpas set up a Specialist Placement Service (SPS) which directly refers these women into NHS services. Over 2016 and 2017, the team managed placements for more than 2,900 women, and the numbers appear to be increasing. In 2017, we received 130 referrals per month, compared to 89 per month in 2015. Most of the women we refer are bpas patients, but about a quarter are referred to us by other independent providers for placement. Reasons for referral are diverse, but the graph below gives the breakdown by principle condition.



They include poorly controlled diabetes, epilepsy and unexplained seizures, asthma, high blood pressure, blood disorders such as deep vein thrombosis, sickle cell disease and haemophilia, stroke, brain tumours, problems with the location of the placenta, and high BMI (morbid obesity). There is evidence that these conditions are increasing in the wider population: for example, increasing numbers of women of reproductive age are affected by cardiac disease in part because clinical advances means more children with congenital heart disease are surviving to adulthood. Meanwhile as more women give birth through Caesarean section, the risk of conditions such as placenta accreta (when the placenta attaches too deeply to the wall of the uterus and places the woman at risk of haemorrage) increases in subsequent pregnancies.

All of these conditions mean that ongoing pregnancy poses a significant threat to the woman's health. More than two-thirds (68%) of the 202 maternal deaths in the UK and Ireland during 2013–15 were known to involve pre-existing medical problems such as those present in the table above – with more than one in ten deaths involving women with cardiac disease.[1] The mortality risk for women with epilepsy in pregnancy is almost 10 times greater than that of the general maternity population (100 versus 11 per 100,000 maternities respectively) and for sickle cell disease three times that of the general population.

The SPS is able to refer into 35 NHS services across England which vary in the gestational age at which they will accept women for care and what kind of abortion procedure they are able to offer (see graph below).



	<12	12	13	14	15	16	17	18	19	20	21	22	23
Medical	33	23	20	20	18	17	14	10	4	3	1	1	1
Surgical	34	31	16	10	9	8	7	6	4	4	2	2	2

The number of potential referral locations is highest in the first trimester which means we can find appointments within a hospital setting for women presenting at the earlier gestations, although the wait for these appointments can push women from needing a first trimester abortion to needing treatment in the second trimester.

These delays present physical challenges and stress for women and, although abortion is very safe, increases procedural risks which increase as gestational age advances.

[1] Saving Lives, Improving Mothers' Care: Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2013–15, MBRRACE-UK, December 2017

- Mother of two, has cancer, awaiting treatment which cannot be performed while she is pregnant. Concerned about the risk of delaying treatment for her long term health. Presented at 9+4. First contact to treatment = 45 days

- 18 years old with uncontrolled epilepsy, had a seizure in week prior to appointment at bpas. Presented at 5+2. Wait from specialist placements referral to treatment = 29 days.

- 22 year old with an autoimmune disease, blood disorders, and mental health problems. Presented at 15+2. First contact to treatment = 44 days

As well as medical conditions, clients also may have multiple complex needs.

- Client has epilepsy and learning difficulties. Refused by nearest hospital as client did not fall under CCG, therefore no funding for treatment. Other nearest hospital has gestational limit of 13 weeks which client will now miss. Offered appointment at farther hospital but could not attend 2 separate appointments as she does not drive and has children at home. Treatment finally booked in London, nearly 7 weeks after initial consultation.

A key area of concern is that as gestation advances through the second trimester the number of potential referral locations decreases dramatically - and is most limited above 18 weeks gestation. This can present serious problems when women first present into the second trimester.

Unsurprisingly many of the reasons some medically complex women present at later gestations are exactly the same as the reasons why women who are not medically complex present later. [2] Often women are using contraception which alters bleeding patterns, so they do not suspect they are pregnant. Even in cases where they are aware they are pregnant, intentions for planned pregnancies can change for any manner of reason - the breakdown of an existing relationship, a dramatic change in financial circumstances or the illness of a child.

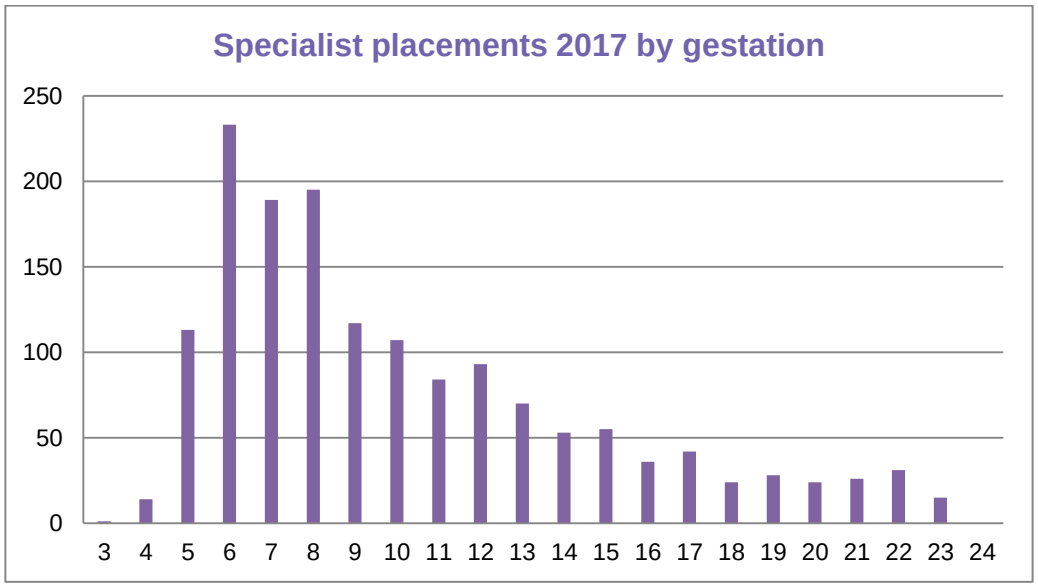
- Client has Type 1 diabetes. Although pregnancy was initially wanted, partner has just lost his job. Cannot afford travel to London for treatment, local agencies cannot help. Bpas funds travel. Client presented at 14 weeks, termination takes place 5 weeks later.

[2] Bpas, '"But I was using contraception..." Why women present for abortions after 20 weeks.'

For the women referred to our specialist placements service, their medical condition may also have contributed to their later presentation for abortion care. Their condition may have suppressed their periods, masking the symptoms of pregnancy, while others will have been led to believe that they could not conceive. A thyroid disorder for example is known to impact upon fertility, while women with a higher BMI are often told their weight will affect their ability to get pregnant. It can also be the case that as a pregnancy progresses, their medical condition worsens or they can no longer physically cope with a previously wanted pregnancy.

- Client wanted a baby, she is now very concerned about her physical health (she previously suffered a heart attack) and is worried she may not be able to care for her existing child.

In 2017, 6% of the women were at 20 or more weeks of pregnancy when they were referred to our specialist placements team. Nationally, 2% of abortions take place at over 20 weeks gestation.[3]



There are only three NHS services which offer treatment up to the legal limit of 24 weeks on all grounds, all in London. These services will suffer from lack of coverage when the doctor is on leave or is for some other reason unable to conduct a surgical list or find a bed on a ward for a medical induction.

The women unable to access abortion care

In 2016 and 2017, we were unable to find treatment for 46 women – so on average, twice a month bpas is unable to find placements for women. Although we receive some non-bpas referrals into our SPS, ultimately overall we only see a third of all women presenting for abortion care across the UK. This suggests that the numbers

[3] Department of Health abortion statistics 2016

of women unable to access care will be higher - and it is reasonable to assume that every week a woman with medical conditions is unable to get the abortion she needs.

As such, on a regular basis, women must continue pregnancies they wanted to terminate, which are medically complex from an obstetrical perspective, and which can pose a risk to their health and their life.

Examples of women for whom no appointment could be found during 2016 and 2017:

- Pulmonary fibrosis and range of medical problems. Pregnancy was planned, but her health has sharply deteriorated, and has decided on TOP as she "needs to be well" to care for her existing child. Presented at 22 weeks. No appointment available.

- Teenager who recently left foster care. Lives alone and feels unprepared to become a parent. Thyroid condition. Contacted bpas at 22 weeks. No appointment available.

- Heart condition. Presented at 22 weeks, Currently attempting to get a non-molestation order against ex-partner due to domestic violence. Has a child with a serious illness. No appointment available.

- Presented at 23 weeks. Client has had multiple surgeries for arteriovenous malformation**,** embolization, and amputation. Weakness in her blood vessels are causing her health to deteriorate. No appointment available.

- High blood pressure and supraventricular tachycardia, presented at 14 weeks. Is currently awaiting sterilisation, was using depo but it had run out. All existing children in care, most recent just a year ago. She said she could not cope with having another baby taken away. Could not attend her first appointment and no other appointment available.

- Has weekly epileptic seizures with symptoms of pre-eclampsia. Suffers from depression and agraphobia. Has young child not currently in her care who was removed due to domestic violence. Concerned about impact medication would have on baby. Presented at 22 weeks. No appointment available.

- Mother of 3 including one child aged under 12 months. Presented at 17 weeks. Surgical termination prep stopped due to spontaneous supraventricular tachycardia (SVT) (heart rate of over 100 heartbeats a

minute.) Echocardiogram showed moderate to severe impairment of left ventricular. No appointment available.

- BMI over 40. Existing children. Pregnancy is the result of a sexual assault. Presented at 22 weeks. No appointment available.

- Has two existing children. Made initial contact at around 17 weeks, but was then hospitalised for three weeks. Suffers from asthma and mental health problems. No appointment available.

- Teenager. Non-epileptic attack disorder recently diagnosed. Feels she would struggle to look after a child. Presented at 19 weeks. No appointment available.

Because there are so few locations where this particular group of women can be treated, many will be forced to travel significant distances to access services. Moreover, second trimester abortions are more complex and time consuming than first trimester procedures; they make 2 days to complete, and therefore can require an overnight stay.

Many women are unable to afford to travel away from home for extended periods, often because they have childcare responsibilities or do not have the financial resources to make the trip - even though bpas will do everything it can to assist. For the following women, the distance required to travel was an insurmountable barrier, and they therefore had to continue their pregnancy:

- 19 years old with three young children. BMI>40. Her ex-partner has recently been released on bail following a prison sentence for domestic violence. Presented at 19 weeks. No suitable appointment available.

- Contacted bpas at 15 weeks. Has recently had a heart attack. She is unable to travel far for treatment as she cares for her existing children and disabled partner. No suitable appointment available.

- Single mother in her late 20s to young children. Multiple miscarriages. Suffers from a number of mental health conditions and unable to travel far for termination. Presented at 16 weeks. No suitable appointment available.

- BMI over 40. 18 weeks pregnant. Daughter was recently violently assaulted and raped; she feels unable to cope with both a new baby and supporting her daughter through this experience. Cannot stay overnight and leave her other children. No suitable appointment available.

- 19 years old, suffers from uncontrolled epilepsy. Concerned about her mental health and ability to look after a child. Unable to travel significant distance for termination. No suitable appointment available.

What is needed?

a) Contraception cannot prevent abortion, but significant improvements can be made to ensure women with medical complexities receive specialist contraceptive care to find the method that is most suited to them and their individualised medical and personal needs. Difficulties accessing contraception, and poor advice, can mean women are left with a suboptimal method, or may be led to believe their condition will mean they are unlikely to become pregnant.

The most recent MBRRACE-UK report highlighted the need for more effective pre- or post-pregnancy counselling of women with pre-existing conditions on contraception. The report authors noted: "It was clear that many professionals caring for women did not consider it their responsibility to counsel them concerning the risks of pregnancy, nor to provide contraception or contraceptive advice, and on some occasions had not even considered the possibility that a woman of reproductive age might become pregnant."

The importance of specialist contraceptive services and consultants should not be overlooked in improving the care of these women. We endorse the recommendations of the Advisory Group on Contraception that Health Education England (HEE) should ensure adequate training for healthcare professionals on contraception, including training numbers for consultants leading and delivering complex care.[4]

b) Locating additional NHS sites or regional hubs where women can be treated and establishing a national tariff for treatment to ensure NHS providers are appropriately reimbursed. Medical education also needs to include termination of pregnancy, and young doctors given the opportunity to train in this area of care, with the collaboration of the independent sector. The Department of Health is currently working with the Royal College of Obstetricians and Gynaecologists (RCOG) and NHS England to develop a new approach for this crucial area of clinical practice, and the RCOG has established an Abortion Taskforce to improve women's access to high quality abortion care. Bpas will support these initiatives in every way it can.

[4] Cuts, Closures and Contraception: The Advisory Group on Contraception; November, 2017

c) Decriminalising abortion through the removal of Section 58 and 59 of the Offences Against the Person Act, which made procuring or providing an abortion a criminal offence, and allowing it to be regulated in the same way as other women's healthcare procedures. The 1967 Abortion Act did not scrap those provisions, it merely provided exemptions to prosecution when women and doctors met specific criteria. The fact that abortion continues to sit within the criminal law can have a chilling effect on medical practice, recruitment, and doctors' willingness to authorise abortions, and therefore women's ability to access this care. In recent years, those opposed to abortion have sought to use the criminal law provisions to call for the prosecution of doctors, and during this current parliamentary session anti-abortion MPs have continued to press the government on the potential for the prosecution of doctors who fail to fill in the legal paperwork that is unique to abortion correctly.

A study from the University of Kent published in 2017 found that doctors providing abortion care were concerned that the threat of prosecution has a negative impact on the recruitment and training of new clinicians in the field and doctors' willingness to provide legal authorisation for terminations. One doctor interviewed stated:

"It makes doctors frightened. Apart from the fact that it's a Cinderella position anyway because it's not seen as part of normal obs and gynae and on top of that they're now also frightened because they say, "Well if we don't cross this and if we don't tick that then somebody's going to take our registration away"…it's got nothing to do with good clinical care." [5]

Bpas believes strongly that decriminalisation of abortion needs to go hand in hand with efforts to improve the service delivery framework. The Royal College of Midwives, the Royal College of Obstetricians and Gynaecologists, the British Medical Association and the Faculty of Sexual and Reproductive Health all support decriminalisation, alongside dozens of women's advocacy organisations.

Conclusion

Pregnancy is not a neutral state of being. It has significant physical implications for all women, but those implications can be profound for those women with existing medical conditions – which can even put their lives at serious risk. We must recognise this, and ensure a medical and legal framework which means those women can obtain the treatment they need, when they need it.

bpas, March 2018

[5] Doctors who provide abortion: their values and professional identity; University of Kent, 2017