









#### Published May 2021

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BPAS provides contraception, abortion, miscarriage management and pregnancy counselling across the UK. We advocate for reproductive rights and a future in which all women are empowered to make their own decisions about their own pregnancies.

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Decolonising Contraception is a community-based organisation created by Black & people of colour working within sexual and reproductive health.

We are grateful to Decolonising Contraception for leading a safe-space workshop to explore the relationship that people of colour have with LARC methods.

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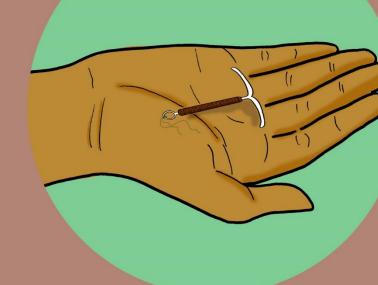
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Shine Aloud UK is a sexual & reproductive health social enterprise based in North London that develop creative solutions to tackle sexual health inequalities among marginalised groups.

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# Long-acting reversible contraception in the UK

British Pregnancy Advisory Service
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# About the report

The report that follows uses existing evidence and information for the background and discussion which is referenced using footnotes. The footnotes include hyperlinks that will connect you directly to the reference where available.

The empirical data i.e. the material that was collected as part of the project and is included to support our findings, is presented in quotation marks with a label that indicates where this information came from (i.e. participant interview, survey etc.). If words or short phrases are included within the text (rather than a quote box), this is also verbatim from the participant to whom the section relates.

To protect the anonymity of our 'LARC user' participants as a standard only the pseudonym, mode of taking part (interview, survey, or workshop) and age of the participant is included. Other information about the participant demographics is available in aggregated format in tables in the <a href="Methods section">Methods section</a>. The 'LARC professional' participants included clinicians, social care staff, academics and activists. Some of these individuals opted to use their own names and organisations in the report. As a standard the excerpts from LARC professionals are labelled with the name (own name or pseudonym) and their sector/s of work.

In the first instance other names will be written in full, subsequently the acronym only will be used. A glossary of terms follows here:

AGC- Advisory Group for Contraception

APPH SRH - All party parliamentary group on sexual and

reproductive health in the UK

CQUIN – Commissioning for quality and innovation

FSRH – Faculty of sexual and reproductive healthcare

IUD – Intrauterine device

IUS – Intrauterine system

LARC- Long-acting reversible contraception

NICE – National Institute for Health and Care Excellence

PHE – Public Health England

QOF – Quality outcome framework

RCOG – Royal College of Obstetricians and Gynaecologists

SRH – Sexual and reproductive health

WHO- World Health Organization

# Statement: Implications of Covid-19

The data collection that underpins this project started in 2019 prior to the Covid-19 pandemic and finished in May 2020, shortly after the first UK lockdown/s began. In the report that follows we have referenced some of the implications of Covid-19 on LARC provision. However, we offer here a specific Covid-19 statement for two reasons: 1) to acknowledge the disparity between circumstances in the sexual and reproductive health sector when data collection commenced, compared to the current situation at the time of publication of the report; 2) to explain how the findings of this report continue to be meaningful (arguably even more so) in the current situation; and how they are imperative to consider 'post Covid-19'.

First, we identify that some of the findings included in this report may be perceived as contradictory to the current landscape of LARC provision whereby users and providers alike are struggling to access and provide sexual and reproductive health care at all due to services being suspended. In some cases, services have come to a halt, whilst others have been operating a reduced capacity and only seeing people with severe symptoms face-to-face. Overall resources are significantly strained including because of limited staff due to redeployment. It is crucial to emphasise that the nature of this report is not intended as a challenge to LARC providers working in precarious and adverse conditions. Instead the report is grounded in a commitment to improving conditions for LARC users and providers alike with the intention of safeguarding future use of LARC for those who want it and those who require LARC removal. This is important to maintain the autonomy and uphold the human rights of all (potential) users of sexual and reproductive healthcare services.

We suggest that this is important now more than ever as the Covid-19 pandemic continues to exacerbate the already fragile sexual and reproductive service landscape that has resulted from years of chronic underfunding. Naturally, in the post Covid-19 recovery period, cost-effectiveness of services and interventions will be high priority. In this context acknowledging users as experts in their own experiences and bodies and facilitating them to select the method that best suits them is likely to increase rather than reduce the cost effectiveness of service delivery as method use is sustained.

This report can function to highlight the ways in which reproductive rights can be eroded, however unintentionally, particularly when the views of those who continue to experience challenges and barriers when accessing sexual and reproductive healthcare continue to remain absent from the conversation; and to stress that any measures taken to cost-save should not be at the expense of a service user's autonomy. Indeed, history offers us both national and international lessons about the impact and aftermath of crisis on the rights of a nation's population. Rather than the findings in this report being a 'threat' to LARC and the LARC provision system, we consider them instead as important evidence to help safeguard the rights of LARC users and the professional standards of providers at this time of collective vulnerability.

# **Summary**

Long-acting reversible contraception methods (sometimes called 'LARC') are increasingly popular in the UK.<sup>1</sup> These methods – the implant, intrauterine device (IUD), intrauterine system (IUS) and contraceptive injection ('depo') – are highly effective at preventing

pregnancy. They last for months or years and because they are usually inserted and removed by a healthcare provider, there's less room for the 'user error' that can reduce effectiveness in other methods like the contraceptive pill or condoms.<sup>2</sup>

LARC can offer many benefits for individual contraception users and for the health system. For some users, LARC methods can be a reliable, private option to exercise greater control over the consequences of sexual encounters. For policy makers and providers, increased uptake of LARC can reduce numbers of unintended pregnancies and be more cost-effective for the health service.3

However, some people from marginalised groups have expressed concern that LARC methods are disproportionately targeted at their communities.<sup>4</sup> More recent concerns in the UK range from how funding cuts and the fragmentation of services can jeopardise access to appointments and reduce range of methods available,<sup>5</sup> to whether some people may feel pressure to use LARC or delay removal,6 to whether it is ethical to require LARC uptake for access to government-funded support services.<sup>7</sup>

A goal of the report was to bring a human rights perspective to how we think about LARC in the UK. This human rights perspective means the report-

- is based on individual's accounts of their own experiences; and
- focuses on those areas where things have gone wrong or care has fallen short of the agreed standards.

This does not mean that we do not acknowledge the benefits of LARC or the positive experiences of many users. We also understand that people providing LARC and LARC services are overwhelmingly motivated to improve people's health and wellbeing. However, our intention in this report is to share some of the challenges involved in LARC provision with the hope that this critical perspective will ultimately support a rights-based provision of LARC and best user experience possible.

<sup>&</sup>lt;sup>1</sup> NHS Digital (2019) Sexual and Reproductive Health Services (Contraception), England, 2018/19 [NS]

<sup>&</sup>lt;sup>2</sup> See NHS (2020) Your contraception guide

<sup>&</sup>lt;sup>3</sup> See National Institute for Health and Care Excellence (2005) <u>Long-acting reversible contraception</u>, and Public Health England (2018) Contraception: Economic Analysis Estimation of the Return on Investment (ROI) for publicly funded contraception in England

<sup>&</sup>lt;sup>4</sup> Dorothy Roberts, Killing the Black Body: Race, Reproduction, and the Meaning of Liberty (Penguin, 1997); Jacob's Institute of Women's Health (2016) Long-acting reversible contraception: Overview of Research & Policy in the United States, Beverley Bryan, Stella Dadzie, Suzanne Scafe, Heart of the Race: Black Women's Lives in Britain (Verso, 2018)

<sup>&</sup>lt;sup>5</sup> See Royal College of General Practitioners (2017) <u>Sexual and Reproductive Health: Time to Act</u>; and APPG SRH (2020) Women's Lives, Women's Rights: Full Report

6 See Elspeth Wilson (2019) 'Why contraception needs a 'Me Too' Movement'

<sup>&</sup>lt;sup>7</sup> See Alison Scott (2019) <u>'Why we must support women to make their own contraceptive choices</u>; Maria Fotopoulou and Tessa Parkes (2020) Why we need to ask questions about the birth control conditions attached to treatment for women who ask drugs; Wale and Rowlands (2020) The ethics of state-sponsored and clinical promotion of long-acting reversible contraception, Broadhurst et al. (2015) Vulnerable birth mothers and repeat losses of infants to public care: is targeted reproductive health care ethically defensible?

The purpose of this project is to expand the critical conversation on how LARC services can best support the reproductive rights of all people in the UK. To do this we spoke to a range of LARC users and professionals about the goals, challenges, and realities of LARC care. We evaluated these experiences against the World Health Organization's (WHO) standards for human rights in contraception services, with a focus on access, informed decision-making and non-discrimination.

'LARC professionals' in this project refers to a diverse range people with roles within which there is interest in or engagement with LARC users and LARC provision this includes: social and health care providers, activists and academics

'Black and People of Colour' is the preferred terminology used by the Decolonising Contraception team when referring to those experience marginalisation due to racism. However, we acknowledge the limitations of this term and that other terms such as 'BAME/R' – Black, Asian, Minoritised Ethnicities - are widely used.

This project is inclusive of all gender identities and recognises that many people may have a requirement for long-acting reversible contraception methods who do not identify as women. We will use gender-neutral language when referring to populations of users or where the gender identity of individuals or a group is unknown (for example 'LARC users' and the individual pronoun 'they'). We use gender-specific language where individuals have shared their gender-identity with us.

We believe it is particularly important to examine the UK LARC provision framework in light of the history of State intervention in people's reproductive lives. While contraception is often celebrated as a force of empowerment, it has also been used historically by the State to control the fertility of groups whose reproduction is not valued. The UK's own history of the contraceptive injection Depo-Provera, an early popular LARC, begins with leading Black women's groups mounting campaigns against coercion in the tailored delivery of the injection to Black, poor and migrant communities. Groups including the Organisation of Women of African and Asian Descent (OWAAD), the Brixton Black Women's Group and Campaign Against Depo-Provera (CADP) led successful campaigns raising awareness of the injection's effects and challenging its targeted use towards working class and ethnic minority communities.

Between December 2019 and May 2020, we conducted research with LARC service users and LARC professionals.

- LARC service users: we ran an online survey with 983 respondents of whom 53.9% were current LARC users;
- LARC service users: we conducted 22 one-to-one interviews and ran a safe-space workshop with 7 self-identifying Black and People of Colour participants.
- LARC professionals: we conducted 18 one-to-one interviews with professionals involved with the provision of LARC in the UK.

Full ethical approval for this project was obtained from Lancaster University Research Ethics Committee in December 2019. The accounts obtained were analysed thematically using a

coding framework developed by three members of the research team. This report presents findings derived from coding across the experiences of our participants against the WHO standards for human rights in contraception services.

The key findings echo those of the recent All-Party Parliamentary Group's for Sexual and Reproductive Health (APPG SRH) that the UK is failing to ensure accessible services for LARC provision for those who want to use it.<sup>8</sup> It is also failing to equip providers with the resources necessary to provide an accessible, comprehensive contraceptive service inclusive of LARC.

In addition, potential users who are ambivalent about LARC, or who do not want to use LARC methods, report pressure to use LARC methods. Providers also report pressure from their organisations, from commissioner-set targets or from the professional norms related to efficacy and cost-effectiveness, to secure uptake of LARC methods over and above other contraception options. These factors compromise users' rights to informed decision-making and non-discrimination in the provision of services.

The report will make *preliminary* recommendations about LARC provision. However formal consultation work based on the findings presented here will be undertaken further to the publication of this report. This collaborative venture will generate meaningful recommendations suitable to different stakeholder groups. These will be published separately as an addendum to the report.

<sup>&</sup>lt;sup>8</sup> APPG SRH (2020) <u>Women's Lives, Women's Rights: Full Report</u>

# Recommendations

An understanding and explicit commitment to Reproductive Justice in the UK context from the 'top down,' cascaded through SRH services, would be invaluable to safeguard rights in LARC provision.<sup>9</sup> Consistent with the findings of this report about LARC provision in the UK context, we conclude that the sector requires some improvement to deliver person and rights centred LARC services. Our initial recommendation areas and definitions are as follows:

 Legitimacy – working to ensure modes of LARC provision always have a 'legitimate' (nondiscriminatory) aim and outcome e.g. welfare. This also includes working to directly tackle stereotypes related to race, sex, gender, age and other characteristics of LARC users.

These are *preliminary* recommendations about LARC provision drawn from the research findings by the project team. Formal stakeholder consultation work will be undertaken further to the publication of this report. This collaborative venture will generate meaningful recommendations suitable to different stakeholder groups which will be published separately as an addendum to the report.

- Accessibility— equitable
   access including for removal of LARC methods. This includes consideration of who is
   included and excluded by a LARC service or initiative.
- Resources to permit time, safe space, conversation and information sharing to support fully informed consent.
- Challenge challenging assumptions and norms about LARC. A recognition that there is no universal 'one size fits all' in relation to LARC and wider SRH services.

Following are some prompts to consider in relation to each of the recommendation areas.

# Legitimacy

- The aim of guidelines and practice targets may be legitimate (e.g. welfare, improve contraceptive method mix) but are there unintended outcomes? What novel or existing tools can we use to protect against discriminatory consequences?
- What role do stereotypes play in who we think is 'best suited' to LARC and what stereotypes do current ways of providing LARC reinforce?
- Do certain characteristics always mean 'LARC is best?' E.g. if someone has a health condition, multiple sexual partners, is young, does that mean LARC is always the best option?
- What is the role of material resources in making LARC users included (or otherwise)? e.g. implant dummy skin colour, marketing materials and layout of the clinic space.

<sup>&</sup>lt;sup>9</sup> See for example: Ross (2018) <u>Reproductive Justice as Intersectional Feminist Activism;</u> Ricky Solinger and Loretta Ross, Reproductive Justice: An Introduction (University of California Press, 2017)

### Accessibility

- Accessibility relates to more than opening hours and disabilities adaptations what other things are important to support/include people in spaces where LARC is provided?
- Who is typically absent from spaces that provide LARC? Why may that be? E.g. people
  with dependents, full-time workers, Black and people of colour service users, LGBTQ+
  people
- What is the role of monitoring in understanding who currently accesses LARC services and the mechanism for finding out how this could be improved?
- How can the LARC removal offer best match the offer for LARC insertion to empower LARC users and potential users?

#### Resources

- Resources are limited in what ways could existing resources be reformulated to better meet the needs of LARC service users?
- In what ways can we diversify resources to ensure LARC users have access to information that's meaningful and trustworthy to them?
- Clinical factors are not the only thing that matters to LARC users social, emotional, political, economic and practical factors all matter too. To what extent does providing only clinical information limit users experience of 'fully informed decision-making'?

# Challenge

- LARC is very effective for the healthcare system if use is sustained. However, for many users the most effective methods are not necessarily the most desirable consider other factors that matter to the user too.
- How do LARC user and LARC provider priorities align and how are they mismatched? What can be done to reconcile the two?
- In considering contraception 'user error,' it is important to remember that abortion and/or unintended pregnancy is not the 'worst possible' outcome for many people.
- Histories matter both individual life history experience and collective histories.
   Many groups and individuals have good reason to feel distrustful of LARC (provider-dependent) methods and associated practices.
- 'LARC is best' how can we be LARC inclusive to widen contraceptive choice, avoid method-centred, directive counselling and maintain person-centred care?



# **Background**

The term 'Long-acting Reversible Contraception' (hereafter 'LARC') is used to describe contraception methods that require administration less than once in a menstrual cycle or once a month. In the UK, this includes:<sup>10</sup>

- Contraceptive implant (effective for three years);
- Intrauterine device, sometimes called the 'IUD' or 'copper coil' (effective for 5 or 10 years);
- Intrauterine system, sometimes called the 'IUS' or 'hormonal coil' (effective for 3 years or 5 years);
- Contraceptive injection, sometimes called 'depo' (effective for 8 weeks or 13 weeks).11

Over the last 15 years, the UK has championed LARC as highly reliable, cost-effective methods of preventing unintended pregnancies. For example:

- The leading 2005 clinical guideline of the National Institute for Health and Care Excellence (NICE) (updated July 2019) recommended increased LARC uptake on the basis that its effectiveness does not depend on the person remembering to take or use the contraceptive.<sup>12</sup>
- England, Scotland and Wales have aimed to improve access to LARC and information about LARC in all recent reproductive and sexual health policies.<sup>13</sup>
- Pay for performance targets e.g. Quality Outcomes Framework (QOF) indicators, used in primary care<sup>14</sup>; and commissioning frameworks e.g. Commissioning for Quality and Innovation (CQUIN), have been used to encourage counselling about LARC methods.<sup>15</sup>

Although improvements in awareness about LARC methods and a wider contraceptive menu are beneficial for contraception users as they broaden their options, the translation of policy and guidelines into practice may present challenges. For example, in the NICE pathways 'Commissioning and planning contraceptive services for under 25s' it is suggested to: 'Use CQUIN indicators and other arrangements and processes to *improve the uptake of effective* 

<sup>&</sup>lt;sup>10</sup> Note: the Faculty of Sexual and Reproductive Healthcare (FSRH) has provided advice during COVID-19 that some LARC forms are very likely to be effective for contraception for a year or more, longer than is usually recommended: for the full advice see: FSRH (2020) <u>Advice for women seeking contraception</u>, abortion and other sexual and reproductive healthcare during the COVID-19 pandemic

<sup>&</sup>lt;sup>11</sup> The contraceptive injection is not universally considered LARC because it requires more frequent administration than the others. In particular Scotland does not include the injection in LARC reporting. We have included the injection in this report but we acknowledge the variation between the methods within the broad 'LARC' shorthand.

<sup>&</sup>lt;sup>12</sup>See NICE (2019; p5) <u>NICE impact: sexual health;</u> NICE (2019) <u>Long-acting Reversible Contraception: Clinical Guidance</u>
<sup>13</sup> Department of Health (2013; p4, 33) <u>A Framework for Sexual Health Improvement in England</u>; The Scottish Government (2015; p10-11, 14, 51, 69) <u>The Sexual Health and Blood Borne Virus Framework: 2011-15</u>; and The Scottish Government (2015; p4) <u>Sexual Health and Blood Borne Virus Framework: 2015-2020 Update</u>; Public Health Wales (2018; p10) <u>Sexual Health Review 2017/2018</u>: A Review of Sexual Health in Wales

<sup>14</sup> Ma et al. (2020) Impact of a pay-for-performance scheme for long-acting reversible contraceptive (LARC) advice on contraceptive uptake and abortion in British primary care: An interrupted time series study; Arrowsmith et al. (2014) Impact of Pay for Performance on Prescribing of Long-Acting Reversible Contraception in Primary Care: An Interrupted Time Series Study

<sup>&</sup>lt;sup>15</sup> See NHS (2020) Commissioning for Quality and Innovation for more information about the CQUIN scheme. Ultimately the scheme, started in 2009, is a payment framework defined by individual Clinical Commissioning Groups (CCGs) that makes services income conditional on demonstrating improvements in quality and innovation in specified areas of care.

methods of contraception, as appropriate' - the vagaries of which may create space for problematic implementation in practice, albeit unintentionally.<sup>16</sup>

Furthermore, this enthusiasm for LARC methods is also increasingly directed at certain 'population groups' in certain contexts, with health and social service agencies having introduced a range of initiatives to facilitate LARC uptake as follows:

- NICE guidelines prioritise the provision of LARC methods to women seeking emergency contraception and abortion services to reduce future unplanned pregnancies.<sup>17</sup>
- Drug and Alcohol Strategies to reduce alcohol-exposed pregnancies includes work to increase the availability of midwife-provided LARC to vulnerable groups.<sup>18</sup>
- The Department for Education and Cabinet Office (via the Tampon Tax) has funded Pause, a project that offers women who have experienced, or are at risk of, having their children taken into care an intensive support service; which has been conditional on the woman agreeing to use a LARC for the 18-month duration of the programme.<sup>19</sup>
- Women postpartum should be advised of the 'superior effectiveness of LARC.'20

Of course, these strategies are motivated by patient and child welfare and clinical contraindications, not just social and economic cost-savings. Indeed, much of the effort to stress the availability of LARC is arguably a response to the tenacity of 'myths and misperceptions' about LARC methods which have limited user choice and hindered uptake.<sup>21</sup> However, in policy and guidelines it often states, for example: 'all methods of contraception including LARC,'<sup>22</sup> with the emphasis on LARC here presumably intended to improve full contraceptive choice. This framing also risks elevating LARC to a superior status 'over' or 'before' other methods paradoxically *reducing* choice. Increasingly there is concern from various quarters about the way the way these policies and guidelines are being implemented.<sup>23</sup>

The UK LARC provision framework raises concerns about 'targeting' and pressure but there are also clear challenges related to resource and access. Most recently an inquiry by the All Party Parliamentary Group for Sexual and Reproductive Health (APPG SRH) has comprehensively illuminated the challenges in their report 'Women's Lives, Women's

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<sup>&</sup>lt;sup>16</sup> NICE (2014) Commissioning contraception services for under-25s

<sup>&</sup>lt;sup>17</sup>National Institute for Health and Care Excellence, 'Contraception' (Quality standard, NICE, 8 September 2016)

<sup>&</sup>lt;sup>18</sup> Greater Manchester Health and Social Care Partnership and NHS in Greater Manchester, 'Reducing Alcohol-Exposed Pregnancies in Greater Manchester' (Briefing note provided to BPAS on request in 2019); Greater Manchester Health and Social Care Partnership and NHS in Greater Manchester (2019) <u>Programme launched to prevent unborn children being harmed by alcohol</u>

<sup>&</sup>lt;sup>19</sup> This use of the LARC condition was the case at the time of completing the research and writing the report. The Pause model has evolved during this period and the circumstances have changed by the time of publication. Further detailed information can be found in the Non-Discrimination section of the report. For other Pause information see: Katie McCracken et al. (2017; 6, 45) <a href="Evaluation of Pause: Research report">Evaluation of Pause</a>; Pause (2019) <a href="How we work with women">How we work with women</a>

<sup>&</sup>lt;sup>20</sup> FSRH (2017) Contraception After Pregnancy

<sup>&</sup>lt;sup>25</sup> See for example Glasier et al (2008) <u>Attitudes of women in Scotland to contraception: a qualitative study to explore the</u> acceptability of long-acting methods, <u>Brook (2020)</u> Myths about LARC

<sup>&</sup>lt;sup>22</sup> FSRH (2017) Contraception After Pregnancy

<sup>&</sup>lt;sup>27</sup> Wale and Rowlands (2020) <u>The ethics of state-sponsored and clinical promotion of long-acting reversible contraception</u>; An event called <u>Long-Acting Reversible Contraception</u> (<u>LARC</u>): <u>Exploring Ethical Practice and Reproductive Rights in Britain</u>, hosted in Manchester in January 2020, united approximately 40 academics and practitioners who broadly speaking, shared the same concerns about how policy and guidelines were being translated into practice.

Rights'.<sup>24</sup> The 2012 Health and Social Care Act relocated contraception provision in England from the NHS exclusively meaning the responsibility is now shared between Local Authorities, NHS England and Clinical Commissioning Groups (CCGs). This complex and fragmented commissioning structure combined with year-on-year budget cuts have put pressure on the provision of all contraception including LARC. The APPG SRH Report found amongst other things: 1) the 'choice of both method and location of provision is being eroded'; 2) that 'one third of women cannot access contraception from their preferred setting'; 3) and that 'people from deprived or marginalised groups are particularly affected.' In short, mirroring findings by the Advisory Group for Contraception (AGC), that contraceptive and sexual health services are 'at a tipping point.'<sup>25</sup> With lack of accountability also identified as a problematic factor in terms of contraception provision currently, the future of services and what this means for LARC provision is unstable.

In addition, we now face the unfolding impacts of Covid-19 which have been acknowledged globally as likely to disproportionally impact women, girls and people from marginalised groups whilst exacerbating existing sexual and reproductive health inequities. There are signs that the already-precarious access in the UK has worsened during COVID-19, with some services forced to closed entirely. An initial survey of members of the British Association for Sexual Health and HIV (BASHH) published in April 2020 showed 54% of respondents were unable to provide LARC as a preferred contraception. Similarly the specific Covid-19 section in the APPG SRH inquiry identified that LARC services were not only suspended during the March-June 2020 period, but they are likely to be disrupted in the longer term as LARC presents a 'financial and practical disincentive' for providers (especially GPs) for whom they are 'unprofitable.'28

The landscape of LARC provision in the UK is frequently dominated by economic considerations but there are some other 'hallmarks' of LARC provision which are also appropriate to consider in relation to the content of this report.

- It is often assumed that the effectiveness of LARC for pregnancy prevention will mean these methods are seen as more desirable than other options for users.
- UK 'mainstream' framing of contraception and LARC is lacking in historical memory. It
  ignores the ways that provider dependent contraception has been used in oppressive
  ways in the past, and the legacies of this, especially for people who belong to groups
  that have been targeted and oppressed.
- A focus on the way in which actions or behaviours in pregnancy may harm fetuses has led to growing emphasis on the use of LARC in particular women deemed to make a pregnancy "riskier", for example those using certain medications for their own health or with a higher BMI.

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<sup>&</sup>lt;sup>24</sup> APPG SRH (2020) Women's Lives, Women's Rights: Full Report

<sup>&</sup>lt;sup>25</sup> Advisory Group on Contraception (AGC) (2018; 4) At tipping point: An audit of cuts to contraceptive services and their consequences for womer; AGC (2016) 'Private lives, Public health: The changing shape of contraceptive services in England post-2013; RCOG/FSRH (2017) Joint statement on the King's Fund analysis of local councils' planned cuts to public health in 2017/18 in England; Helen Stokes-Lampard et al. (2017) Sexual and Reproductive Health: Time to Act

<sup>&</sup>lt;sup>26</sup> Hall et al. (2020) Centring sexual and reproductive health and justice in the global COVID-19 response.

<sup>&</sup>lt;sup>27</sup> British Association for Sexual Health and HIV (2020) BASHH COVID-19 Sexual Health 'Clinical Thermometer' Survey: Initial Results Snapshot <a href="https://members.bashh.org/Documents/COVID-19/BASHH%20COVID-19%20Clinical%20Thermometer%20Survey%20-%20First%20Round%20Results%20Snapshot%20.pdf">https://members.bashh.org/Documents/COVID-19/BASHH%20COVID-19%20Clinical%20Thermometer%20Survey%20-%20First%20Round%20Results%20Snapshot%20.pdf</a>

<sup>&</sup>lt;sup>28</sup> APPG SRH (2020) Women's Lives, Women's Rights: Full Report

- LARC and wider contraception users are typically presumed to identify as female and heterosexual in ways that may obfuscate the diversity of gender and sexual identity of LARC users.
- LARC and contraception resources in the UK are typically limited in terms of any reference to users' rights<sup>29</sup> which we move to consider in the next section: Human Rights.

<sup>&</sup>lt;sup>29</sup> In contrast, the recent APPG SRH (2020) report is explicitly framed in relation to rights i.e. <u>Women's Lives, Women's Rights.</u>
It does appear that rights are increasingly a feature in conversations in sexual and reproductive health in the UK context.

# Human rights

### What are human rights?

Human rights are the rights and freedoms that belong to every person in the world.

They are based on shared values like dignity, fairness, equality, respect and independence.<sup>30</sup>

# Why are we talking about human rights and contraception services?

The World Health Organization (WHO) has said that it is important for all States to provide contraception services that respect, protect, and fulfil people's human rights.<sup>31</sup>

In particular, the WHO says that States should make sure they meet the following human rights standards in how they provide contraception and information about contraception.

- AVAILABILITY, ACCEPTABILITY & QUALITY: there should be enough open, working services providing respectful care to meet people's needs.
- ACCESSIBILITY: people should be able to find and use these services.
- NON-DISCRIMINATION: services shouldn't treat people unfairly, worse, or make assumptions about what they need because of their race, ethnicity, age, gender identity, religion or sexual orientation.
- INFORMED DECISION-MAKING: people should be able to make their own free decisions about whether to use contraception, what kind, and when to stop.
- PRIVACY AND CONFIDENTIALITY: services should respect people's control over their bodies and over information about them.
- PARTICIPATION AND ACCOUNTABILITY: people should be able to take part in deciding policies that affect them and take action where they are not happy with how they are treated.

#### What does this mean for the UK?

The UK, like other States, must meet these standards in its contraception services. This responsibility comes from the UK's commitments in international human rights treaties and domestic law.

The UK is a party to international human rights treaties that protect the human rights that the WHO has said are important for contraception services. These include:

• The right to health.<sup>32</sup>

<sup>&</sup>lt;sup>30</sup> Equality and Human Rights Commission (2019) <u>'What are human rights?'</u>; United Nations (1948) <u>Universal Declaration of</u> Human Rights

<sup>&</sup>lt;sup>31</sup> World Health Organization (2014) <u>Framework for ensuring human rights in the provision of contraceptive information and</u> services

<sup>&</sup>lt;sup>32</sup> International Covenant on Economic, Social and Cultural Rights, Article 12; and Convention on the Elimination of All Forms of Discrimination Against Women, Article 12 and 16(1)(e) ("CEDAW")

- The United Nations Committee on Economic, Social and Cultural Rights has said that barriers to contraception and lack of accessible reproductive and sexual health services violate the right to health.<sup>33</sup>
- The right to respect for private and family life.<sup>34</sup>
  - o Privacy includes someone's control over what happens to their body.
  - It includes the ability to decide whether or not to have a child and become a parent. It includes choosing the circumstances in which to become a parent.<sup>35</sup>
- The right to enjoy these rights without discrimination of any kind based on any ground such as sex, race, ethnicity, colour, religion, disability, age, sexual orientation or gender identity.<sup>36</sup>

The UK's responsibility to protect human rights is also found in domestic legislation and decisions of Courts.

- The Human Rights Act 1998 incorporates the rights protected in the European Convention on Human Rights.
- The Equality Act 2010 includes a requirement for public authorities (such as the NHS) to think about the need to eliminate unlawful discrimination, advance equality of opportunity, and encourage good relations between people who share a protected characteristic<sup>37</sup> and those who don't.<sup>38</sup>

### Why is this important?

Protecting human rights is important to help make the UK a fair and safe place for all.

Protecting human rights can also help to improve the care that we provide to people.

Human rights set the standards that we can expect public authorities to meet when providing care. When these standards are not met, human rights can give people the power to speak up, to challenge their treatment and to call for change.

<sup>&</sup>lt;sup>33</sup> United Nations Economic and Social Council Committee on Economic, Social and Cultural Rights, <u>General Comment No.</u> 22 (2016) on the right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights)

<sup>&</sup>lt;sup>34</sup> European Convention on Human Rights, Article 8

<sup>&</sup>lt;sup>35</sup> Council of Europe, Women's sexual and reproductive health and rights in Europe (Issue Paper, 2017) 54; and CEDAW Article16(1)(e)

<sup>&</sup>lt;sup>36</sup> Protected in CEDAW, Articles 1 to 2; Convention on the Rights of Persons with Disabilities, Article 5, European Convention on Human Rights, Article 14. See also UN Committee on Economic, Social and Cultural Rights, General Comment No. 20 Non-discrimination in economic, social and cultural rights (art. 2, para. 2), of the International Covenant on Economic, Social and Cultural Rights) (2 July 2009)

<sup>&</sup>lt;sup>37</sup> Protected characteristics are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation: Equality Act 2010, Section 4

<sup>&</sup>lt;sup>38</sup> Equality Act 2010, s 149 and see Equalities and Human Rights Commission, <u>Public Sector Equality Duty</u>

# Non-discrimination

This project was inspired in the first instance by concerns about how some current UK initiatives and practices may disproportionately target certain marginalised groups for use of LARC methods, or place a condition of LARC use on access to services and support such as in the case of Pause. During the life of this research project Pause shifted their position on requiring acceptance of a LARC in order to access their support. This change, which we will cover in more detail later in this section, came about further to an independent review of Pause and evidence that the LARC use condition may create 'ethical tensions' and 'unintended

#### Non-discrimination means:

- services eliminating the stereotypes and prejudices about race, ethnicity, age, gender identity, religion or sexual orientation that can produce pressure for people to make certain contraceptive choices.
- supporting people to access care and make free decisions on an equal basis with others.

consequences'<sup>39</sup> – tensions and consequences that overlap with the 'informed decision making' section of this report. Beyond targeting and conditional use, the accounts of LARC provision that we collected from the interviews with service users expanded our understanding of how LARC support can be unequal.

This section of the report documents how users experience discrimination in relation to LARC provision. It outlines how:

- Services fail to ensure an inclusive environment for all LARC users.
- Services fail to ensure Black and people of colour LARC users, younger LARC users and disabled LARC users are heard and accommodated.
- Assumptions about who can use contraception responsibly and who is ready for
  parenting can limit users' ability to access care and make free decisions about their
  own contraception use.

# LARC User Perspectives

The doctor seemed to have rules about who should get what contraception despite all being viable options in theory. Anon, 21, Survey

# Unequal and exclusive access to support

The <u>Background section</u> highlighted how the UK is currently experiencing significant issues with access and resources related to LARC provision, and that these challenges will disproportionately impact people from disadvantaged and marginalised groups, widening

<sup>&</sup>lt;sup>39</sup> Boddy et al. (2020; 62) Evaluation of Pause

The contraceptive patch is not considered a LARC in the UK (although it is in some other country contexts e.g. USA). The example that follows about the colour of the patch, highlights further some of the discriminatory aspects of LARC provision internationally. This participant was frustrated that the contraceptive patch is only available in a colour designed to blend with a white skin tone.

existing health inequities.<sup>40</sup> We heard directly from our participants how barriers to access can be particularly acute for those LARC users who identify as Black or from minoritised communities, who are considered young (under 18/under 25) and/or those who have a disability. Users described their experiences of services dismissing their concerns and failing to accommodate their contraception needs in myriad ways.

Failures to include Black and people of colour users in posters, marketing, and other service resources is exclusive and can make it hard to relate. This acts as barrier to access. For example, Black participants pointed to the white flesh tone of the implant tester dummy arm:

So the implant tester dummy is[...]like an arm but it's not a full arm. And it just kind of shows you how the implant feels beneath the skin. And the skin on that kind of dummy is white and it's remained white for whatever because the one I saw at 16 to the one I saw in the group interview was still white. So I've never seen a Black dummy where they actually had some like fake black skin and put an implant underneath it to show and normalise it for like young Black people what it looks like underneath the skin. And that's kind of the basis of most sexual health demonstrations with dummies, they are always a white skin tone so I can never see myself in it or know what it would look or feel like almost.

Even though I can see it. NUMBER ONE, 25, Interview

Because I really liked the patch, but it's white, like it doesn't blend in with everything, and that's one of the things that's important it's like really discreet.

Dee, 20, Workshop

Black and People of Colour users valued being able to see a Person of Colour in a healthcare setting with concerns raised about whether they would be heard, and feel comfortable enough in spaces where this was not an option:

<sup>&</sup>lt;sup>40</sup> APPG SRH (2020) <u>Women's Lives, Women's Rights: Full Report;</u> Hall et al. (2020) <u>Centring sexual and reproductive health</u> and justice in the <u>global COVID-19 response</u>

And I felt like because my doctor was a person of colour, like she just understood a bit more and she wasn't trying to baby me or enforce some idea of me that she had before. Dee, 20, Workshop

However, this can also be daunting due to concerns about being recognised or the provider have ties to that community:

I would prefer a Black woman but I also see that Auntie behind the reception that's just looking at me funny, and it's like: OK you've been having sex. Stacey, 24, Workshop

Or being judged against racist stereotypes<sup>41</sup>:

Firstly, I'm a Black woman, you can sometimes be looked at a sexually promiscuous, you're kind of looked at as why are you having sex especially if you're served by members of your own community. So I definitely think there's kind of a stigma there which is why irrespective of someone's race, gender etc., they should bear in mind that this is your experience and it shouldn't be judged and it should be a safe space. Number One, 25, Interview

Services also fail to accommodate different physical needs. Nia, 29 described being "partly shut out" of clinic settings and having to "make do" with very difficult, inaccessible services and facilities for a wheelchair user, including for LARC fittings:

They did ask if I could get up on to the bed, which I couldn't, so I had to sort've lean on to a table, with my arm out, so to get my arm in that position and relax it at the same time was quite difficult because I couldn't on the bed. So, although it was done anyway, you know, it would've been a lot more comfortable and a lot easier if I could've got on a bed. NIA, 29, Interview

The sexual identities of our LARC user participants were diverse e.g. out of 22 LARC user interview participants, only 6 (27%) identified as 'heterosexual.'<sup>42</sup> However assumptions about sexual orientation and gender identification are inherent in many contraceptive services, which also function to exclude:

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<sup>&</sup>lt;sup>41</sup> See for example Ntinu (2017) Hyper-sexualisation: the realities of my black, female body: <a href="https://gal-dem.com/hyper-sexualisation-black-female-body/">https://gal-dem.com/hyper-sexualisation-black-female-body/</a>

<sup>&</sup>lt;sup>42</sup> For full demographics of the different sample groups, see the Methodology section.

I don't often get the choice but I really like when services are openly LGBT friendly [...] the default is like you're having sex with men, like that's it and there's no question about. Dee, 20, Workshop

### Not believed, not understood

Participants' perceptions that they were not heard or believed by their providers were commonplace. Some described how providers would make assumptions about their health based on racial stereotypes:

HOW they talk to you as a young Black woman. In particular parts of the UK, it's like, 'oh this is very typical of you', or 'you're just a number, deal with it', you know. 'Take some ibuprofen', or you know, 'take another anti-inflammatory'. And it's like: why don't you just help me? Kelly, 25, Workshop

'Playing the game' was described when experiencing side-effects as presenting as their 'normal Black self' was not enough to be taken seriously. Stephanie talked for example about preparing for appointments and making sure to bring a full record of medical notes:

Not because I don't trust them as medical professionals, but I don't trust them to believe who I am. So I need to prepare as much as I can to make sure that you give me what I need. Stephanie, 25, Workshop

By contrast, others shared positive experiences when they felt heard by practitioners:

The sexual health clinic I went to at the beginning of the year I saw a Black nurse and I think she had – she was trying to remind herself you know this is not my sister be professional, but we cracked jokes and it just helped me feel a lot more secure and I felt like I was equipped with the proper information, that if this thing doesn't work for me, in the next 6 months, I will be alright.

Melissa, 30, Workshop

Assumptions and stereotypes about other aspects of identity were also included by participants. In particular, the implications of (young) age was a key theme especially from survey participants, for example:

I clicked on this survey because myself and many of my friends at university were pushed to use LARC by mostly female NHS nurses and doctors, even if this was not our preference and we had stated so multiple times before. The insinuation or outright comments made by these medical professionals were that we were too young/irresponsible to use a contraceptive method other

than LARC. These comments were often made repetitively even when we asked for them to stop and seemed to be founded on no other evidence than the stereotype that because we were all young, sexually active woman at university, we must also be irresponsible, promiscuous, and forgetful. These experiences are deeply upsetting and further, I believe that they could stop women getting access to medical care they need and deserve, without shame or prejudice. Anon, 21, Survey

This description of stereotypes about young people, overlaps with perceptions of who is suitable to reproduce and when, discussed further in the next section.

# Suitable to parent?

Who is encouraged to consider LARC, and how, can be driven by perceptions about who is:

- sufficiently responsible to manage user-dependent methods of contraception; or
- 'fit' or 'suitable' for pregnancy.

These perceptions can be based on a provider's professional expertise and an open conversation about the needs and wants of an individual service user. But, worryingly, they can also be influenced by shared assumptions and stereotypes about who will make a 'good mother' and when is the 'right' time to have children. These assumptions, albeit often unintentional, shape and potentially undermine contraceptive choices and access to services.

In academic literature about this topic, the term 'stratified reproduction' has been used to refer to the ways that some users are considered more 'suitable' for reproduction than others.<sup>43</sup> In the UK context and other comparable countries the 'ideal' typically means a 'planned pregnancy' for a white, middle-class, educated woman. Whilst 'stratified reproduction' identifies the "preferential valuing of the fertility of white women of higher socioeconomic status over that of poor women of color"<sup>44</sup> our understanding can be bolstered further if we draw on Intersectionality.<sup>45</sup> Commonly misunderstood as an 'academic' or a 'theoretical concept,' intersectionality is derived from a rich history of Black women's organising and activism (including in relation to sexual and reproductive health) and allows us to consider how oppression is structural and interlinked. Experience of intersecting identities (disability, sexual orientation, gender identity etc.) and the associated interconnecting oppressions further devalues the fertility and reproduction of certain individuals and groups and is relevant in considering (non)discrimination in LARC provision.

Assumptions about who is most 'fit' to reproduce are accompanied typically by the idea that unplanned pregnancy and abortion are the worst possible outcome and should be avoided at all costs- regardless of whether the service user themselves would be content with either outcome if a contraceptive method failed them.

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<sup>&</sup>lt;sup>43</sup> Colen (1995 in Ginsburg and Rapp) Conceiving the New World Order

<sup>&</sup>lt;sup>44</sup> Wu et al (2019) <u>Looking back while moving forward: a justice-based, intersectional approach to research on contraception</u> and disability

<sup>&</sup>lt;sup>45</sup> Ross (2018) <u>Reproductive Justice as Intersectional Feminist Activism</u>

Age is one of the key factors that has long been a preoccupation in relation to sexual and reproductive health with 'youth' and pregnancy being the focus of many public health interventions e.g. the teenage pregnancy strategy. 'Young mothers' are stigmatised<sup>46</sup>; even more so when the person is also working class and/or Black and/or any other characteristic that fails to align with the UK society's version of the (most) 'ideal' mother.<sup>47</sup> Highly pejorative stereotypes for example about Black 'welfare mothers'<sup>48</sup> and 'chav mums' have been identified in academic literature but are also visible widely across our mainstream media.

These assumptions were reflected in the data collected through our interview and survey participants with many describing how providers directly invoked their (young) age to encourage the choice of LARC. Service users talked about providers having a 'fear' of them becoming pregnant and described providers' 'burden' to prevent the 'problem' of 'underage' or teenage pregnancy. Which could translate to an emphasis on LARC:

Contraception is really pushed, especially like something that will stop you getting pregnant for 4 year takes you from an underage pregnancy into a pregnancy in your 20s, and I think that's why it was sold to me at that age.

Anna, 29, Interview.

Users stressed that they thought providers were trying to act in their interests and that they might be under "pressure from the government" to help them avoid pregnancy. But at the same time, they talked about wanting to feel able to make their own decisions- something that could be undermined by stigma and racist/ageist stereotypes, as reflected here:

I think I was like 17-ish then so it was just like 'oh, she's gonna have a teenage pregnancy and she's gonna be another Black single mother' and I'm like [...] I understand the fear, and sometimes it does kinda feel like: 'oh, it's exactly like what my parents are saying.' But then it's also like: you're not my parents and I do kinda want to feel like I'm a respected person when I come to the clinic. **DA, 20, Interview** 

While Tanith understood that practitioners "had success in talking other young people out of having kids young", she emphasised how pregnancy had been the right decision for her but that providers were "prejudiced" about her wanting to have a child aged 19:

<sup>&</sup>lt;sup>46</sup> Yardley (2008) <u>Teenage mothers' experiences of stigma</u>; Wilson and Huntington (2005) <u>Deviant (M)others: The Construction of Teenage Motherhood in Contemporary Discourse</u>

<sup>&</sup>lt;sup>47</sup> See for example Lonergan (2012) Reproductive Justice and Migrant Women in Great Britain', McCarthy (2009)'I have the jab so I can't be blamed for getting pregnant': Contraception and women with learning disabilities', Middleton (2011) 'I Wouldn't Change Having the Children—Not At All.' Young Women's Narratives of Maternal Timing: What the UK's Teenage Pregnancy Strategy Hasn't Heard, Higgins (2014) Celebration meets caution: LARC's boons, potential busts, and the benefits of a reproductive justice approach

<sup>&</sup>lt;sup>48</sup> Ross (2018) Reproductive Justice as Intersectional Feminist Activism

It was just the way they sat down and talked to me. And: 'do you understand a baby RUINS your life[...] and you're so young. Go out and live your life' and to be fair I don't really think that was their place to be offering me any kind of advice. These ladies were professionals. I went to them for a professional service and they kind've overstepped their mark, a wee bit, I think. TANITH, 32, Interview

Consistently, we heard how disabilities may impact on the experience of pressure to choose and keep using LARC. Nia described how medical staff might be inclined to exercise "more caution" towards her choices due to physical disabilities, which in turn compromised her independent decision making:

Although I've got no learning or mental disabilities, it sometimes from my experience, when you see someone physically disabled it's sometimes questioned whether their mental capacity is you know as average, yeh that's the best way to explain it really. NIA, 29, Interview

A recent report by Engender Scotland found disabled women and girls are more likely to be prescribed LARC than non-disabled peers, and that contraception is prescribed earlier and continues later than for non-disabled women.<sup>49</sup> Other studies have found that services can pressure or coerce people with learning disabilities to use LARC because they are more effective for preventing pregnancies that are considered undesirable, and because they are less burdensome for families and service providers.<sup>50</sup>

The data collected also offered insights into the interplay of mental health with LARC use. Both people with pre-existing mental health conditions and otherwise described being 'disbelieved' or 'minimised' in relation to their mental health experiences with LARC, typically to defer a removal request and maintain their method:

I wish I had been taken more seriously both times I had LARC and struggled with the side effects. When I spoke to a contraceptive medical professional about my mental health on the implant I remember them asking me if anything else was going on in my life to make me feel that way, as it was unlikely to be the implant. I feel like I wasted a long time not believing myself and felt instantly better when I had it removed after two years. Anon, 28, SURVEY

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<sup>&</sup>lt;sup>49</sup> Engender, (2018) <u>Our bodies, our rights: Identifying and removing barriers to disabled women's reproductive rights in Scotland</u>

<sup>&</sup>lt;sup>50</sup> Catalina Devandas Aguilar, (2017) <u>Sexual and reproductive health and rights of girls and young women with disabilities</u> and see McCarthy, (2009) 'I have the jab so I can't be blamed for getting pregnant': Contraception and women with learning disabilities; Sarah Earle and others, (2015) Contraceptive choices for women with learning disabilities

For others, mental health medications (e.g. for bipolar disorder) or fears of exacerbation of mental health difficulties through hormonal contraception use meant LARC was their 'only option.' Users' lack of awareness of the impacts of LARC and what is meaningful to users is relevant here and will be discussed in more detail in the section about <u>Informed Consent</u>. However, this person-centred approach (what's best for the individual user) is at risk of being eclipsed in LARC counselling by provider priorities, some of which are discussed next.

### LARC Professional Perspectives

#### Who LARC suits best

Of course, there are various safeguards in clinical practice settings to support decision making for the provider and user. For example, the extent to which a young person is able to consent is assessed against Gillick and Fraser competence respectively.<sup>51</sup> Gillick competence helps to determine capacity to consent to medical treatment and Fraser guidelines are used to decide whether a person under 16 can consent to contraceptive or sexual health advice

and treatment specifically (without parental consent). During a consultation, with an under-16 a professional will go through a checklist of questions to ascertain whether failing to provide them with sexual and reproductive healthcare would hinder their health and wellbeing. Although under 16s are encouraged to talk with their parents and carers about their sexual health needs, they are entitled to confidentiality, providing that any disclosures they make during a consultation do not or will not cause harm to themselves or anyone else.

"You can do something with the best intentions but the unintended consequence of the system being unable to support the effective rollout, is that you may actually hurt the people that you intend to support." INGRID, LARC PROFESSIONAL: Academic

Yet, many LARC professional interviewees contributed their perspectives on how LARC might benefit particular patients or service users; suggesting that younger users may benefit from a more discreet LARC option if they wish to keep their contraception use private from family; or that LARC may be 'easier' for young people to use if they have an irregular routine. Rachel, a Clinical/Academic LARC Professional, reflected on the relevance of LARC for young people with disabilities until such a time they had received the support they needed to be in a position to successfully parent:

And then young people with disabilities, so they tend to rock up in the service when sadly there's been an abusive situation. So you know, run away from home, found on the streets that kind of thing. And then there really is there, you know 'we really should take pregnancy out of the picture'. You know so it's not an overt pressure but you're kind of complicit in that really because you feel the last thing they want right now is a pregnancy until they are sorted out. So you will sort of be going 'it might be good right now to think about the implant for a little while'. They're still in control they can still come

<sup>&</sup>lt;sup>51</sup> CQC (2018) Gillick Competency (2018); NSPCC (2020) Gillick Competency and Fraser Guidelines

back. But maybe, maybe we do emphasise those ones a little bit more. Yeah it is what it is. RACHEL, LARC Professional: Clinical/Academic

The use of LARC methods can be considered to support autonomy and actively enhance the quality of life of users. For example, Janet, a nurse in abortion services, explained how some LARC methods (in particular Depo-Provera) could help to control menstrual bleeding that some users may find distressing:

A lot of people with Depo will end up with no bleeding. And heavy bleeding is difficult to cope with if you've got learning disabilities, it's very upsetting, you know. JANET, LARC Professional: Clinical

Consistent with the recognition of LARC as suitable for specific 'population groups,' as described in the <u>Background section</u>, professional interviewees shared how LARC is valuable for people experiencing homelessness, people using alcohol and drugs, or people with generally "disjointed" or "chaotic lifestyles" where it might be more difficult to remember to take a contraceptive pill at the same time every day or access and use condoms every time you have sex.

So I think that there are certain groups of women that, as a health official you feel that you would like to give them LARC. You would like them to have a LARC. For example, women who've had their children removed, or drug and alcohol users, or women who've had multiple previous abortions, that you might feel like, that you, you'd want to talk to them in more detail about LARC and say: 'look, you know, would you consider it, this might maybe suit you.' HELEN, LARC professional: Clinical

Including as a means to alleviate the worry experience by professionals about a service user falling pregnant (again):

I mean I suppose the concern is ideally, myself, knowing that they're on a longer-term contraception, that's one thing that you can then put aside, you don't need to then worry about them getting pregnant again. I suppose our concern if somebody is on the pill, then that is, that would bring a bit of a concern to me, if I know that person is chaotic and not likely to remember to take their pill regularly. RF, LARC Professional: Social

We heard about how LARC can play a key role in support for women whose children have been taken into care. This can be in response to an assessment that the service users have struggled with user-dependent forms of contraception in the past; or when professionals consider that service users would benefit from avoiding a pregnancy 'right now', so they can focus on other things as is the case with the <u>Pause programme</u>:

So, what we offer is an 18 months voluntary programme to support those women in really building – I guess - strong foundations to help them with whatever they want to go on and do, and part of that programme is a pause in pregnancy. CLARE, LARC Professional: Social

This focus on avoiding pregnancy generally across different types of support services is connected to the perceived likelihood of the service user experiencing (further) care proceedings:

That it's not just a, 'do you know what I mean and not in a sense of we're putting a lot of pressure on you' or 'we're nagging you hard'. But about why we're doing that and for some young people when they've had to make those really difficult choices of a different alternative which is termination or another removal, then thinking about contraception, whether that be LARC or anything is better than that decision, to have to make at that point really. ROWENA, LARC Professional: Social

For Pause, the likelihood that all service users' pregnancies will result in the removal of the child is an explicit part of the cost-saving calculation for local authorities.<sup>52</sup>

# Critical perspectives

Overall the LARC Professionals involved in this report differed about what the benefits of LARC use for particular groups or individuals, meant for how they provided services. At one end of the spectrum, Pause is an example of a service explicitly requiring pregnancy avoidance via (at the time of undertaking the research) use of 'the most effective method of contraception' (following an initial 16-week engagement period) – defined as LARC – in order to receive a sustained wider package of support:

I think there's a much wider context that we're working in that isn't just about asking someone to go on to contraception and then that is it, it's giving them space in their life to do that, take a pause in pregnancy and also do lots of other work, as dedicated professionals that is designed to support them and challenge them and help them. CLARE, LARC Professional: Social

Ultimately, Pause puts forward a vision of promoting freedom of choice for its users that they may have been denied in other areas of life. But on contraception, for several years since its launch, Pause has been clear on requiring one specific choice – the use of a LARC method – to access the many benefits of the funded voluntary programme. This is tied up in the perspectives about how services users can benefit from a pause in pregnancy, and in

<sup>&</sup>lt;sup>52</sup> McCracken et al. (2017; 55, 58) *Evaluation of Pause: Research report*; Boddy et al. (2020; 62) *Evaluation of Pause* 

questions around the service users' capacity to make contraception decisions that will ensure they achieve this.

I think we could question how much choice these women had about their sexual and reproductive health anyway. But also, I think what we're learning is that actually sex and relationship education and information, they just haven't had it. So a lot of women we talk to don't necessarily know how a baby is created and how pregnancy happens and lots of some of that basic sexual health and reproductive health and relationship information that, well, you know our education isn't good. CLARE, LARC Professional: Social

However, Clare acknowledged that there can be "really difficult issues" around choice. Indeed, subsequent to the data collection for this report, and further to the release of the most recent evaluation in 2020, Pause commissioned a review of their policy related to contraception. As a result, Pause no longer require a LARC as the only means of avoiding pregnancy. We understand that Pause continue to require use of contraception to access the programme.<sup>53</sup>

<sup>&</sup>lt;sup>53</sup>See Boddy et al. (2020; 62) *Evaluation of Pause*, which highlights the 'ethical tensions' and 'unintended consequences' of LARC conditionality. The footnotes of this report also reference personal communication from Pause about their intentions to reflect on their contraception policy.

The following explanation of a change in policy regarding LARC use at Pause, was gratefully received by us from Pause on 27 April 2021 specifically for use (with consent) in this report:

#### Pause contraception consultation

One of the areas Pause has recently spent time considering is our approach to the sexual and reproductive health of the women we work with and whether it should be different. Our reflections were prompted by a range of things – what we were learning from the experiences of women, of Practitioners and of other people involved in Pause; the impact of the restricted access to sexual health services that came about for many women at the start of the first COVID-19 lockdown; looking at the results of Practice Quarterly Reports; and the interim findings from the independent evaluation of Pause.

Last year Dr Rebecca French, associate professor in Sexual and Reproductive Health at the London School of Hygiene and Tropical Medicine, undertook a consultation on Pause's position on contraception. In partnership with a graduate of the Pause Programme, Rebecca spent time with a wide range of Pause stakeholders and made a series of recommendations, some for Pause and some for the wider system of sexual and reproductive health support for women. All of those recommendations have been accepted by Pause.

This reflective process has reinforced that the pause in pregnancy women currently commit to on the Pause Programme, is crucial in enabling them to focus on themselves and achieve positive changes in their lives. It has challenged us to consider whether our existing policy on use of Long-Acting Reversible Contraception (LARC) reflects what actually happens in practice and therefore we have made some changes to our policy to better reflect practice. If women now choose to work with Pause, and take a pause in pregnancy, they will be supported to access the most effective and acceptable form of contraception for them — which could be a non-LARC method.

During our research some LARC Professionals were very concerned about the original LARC only Pause approach. Hannah, manager of a women's centre, described how they felt "incredibly strongly" as an organisation about not pursuing the proposition to deliver the Pause model:

We did not see how it would be at all congruent for a feminist service user led organisation to mandate anything about the services we deliver but especially use of contraception because it felt like again, control of women's bodies. That is something that historically has happened in lots of different ways, would never be applied to men etc. And that also brought a lot of issues for us around choice and how you can say that you're offering a choice led user led service if you're mandating anything. HANNAH, LARC Professional: Social

It may be that the revised Pause model, which still expects contraception use in order to achieve a pause in pregnancy, will be more favourably received by some who have expressed concern about the original LARC requirement. Nonetheless, other professionals who took part in this research acknowledged more generally that the relationship between support and contraception could feel "very social engineering really" Lynn, LARC Professional: Social. These direct references to the relationship between eugenics and contraception made here by service providers arguably validate the fears experienced by some users that they will be actively dissuaded from reproduction.

If associations such as those made explicitly between LARC and 'social engineering' or 'eugenics' feel shocking, we suggest this is related to the general lack of historical memory in the UK about the relationship between 'birth control', especially provider dependent methods, and abuse and exploitation of marginalised groups- as discussed in the <u>Background section</u>. By contrast, in other countries this relationship is better acknowledged as a barrier to LARC use. For example, over the last decade USA based literature about LARC considers these links explicitly even in relation to 'directive LARC counselling' i.e. where "one or two LARC methods are recommended over all others" with concerns raised "if we ignore the legacies of racism and eugenics" associated with contraception and possibilities for abuse.<sup>54</sup> More recently the ethical (and eugenic) dimensions of the current LARC framework in the UK are gaining wider coverage with any *conditional* LARC use generally argued against by ethicists.<sup>55</sup>

Other concerns raised by our LARC Professional participants about conditional LARC use linked to how this approach was inconsistent with a trauma-informed model and recent efforts to raise awareness of coercive control:

So we're saying to women it's not right for people to treat you like that. It's not right for people to ask you to behave in a certain way. And then we're asking them to, would be asking them to, behave in a certain way in order to get a certain amount of care and that's just wrong. We don't precondition on health care, we just treat people as individuals and we, we look at them and their situation and we see what we can do to help. I cannot make that strong enough. I can say this strongly - It's just so wrong. ALISON, LARC Professional: Clinical

Indeed, the importance of *retaining* choice over childbearing following experience of removal was highlighted:

Just because you lose your children doesn't mean that you have no control over your fertility. It's a massive social assumption, in my view. And that if you lost your children the idea that you wouldn't want another child is also a really erroneous assumption. Wanting another child is the only, might be the

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<sup>&</sup>lt;sup>54</sup> Higgins (2014; 238) <u>Celebration meets caution: LARC's boons, potential busts, and the benefits of a reproductive justice approach</u>

Wale and Rowlands (2020) The ethics of state-sponsored and clinical promotion of long-acting reversible contraception; Boddy et al. (2020; 62) Evaluation of Pause

only hope that you have. And actually having some control over your fertility might be the only control you have left. The idea that one day you might be able to have another child, is might be the only hope that keeps you alive.

LYNN, LARC Professional: Social

Instead of requiring LARC use as a condition, some LARC professionals talked about focusing on improving the access to available contraception services for those services users who are typically 'targeted'. This could include arranging for a contraception and sexual health nurse to visit a programme or a 'fast track' arrangement, whereby service users would be able to avoid the uncertain wait and inconvenient appointment times of local clinics. This is consistent with recommendations that 'enhanced care' for specific disadvantaged groups is in fact, an ethical responsibility for professionals in order to provide best care and reduce harm.<sup>56</sup> Alternatively, some LARC Professional participants suggested improving information gaps for the client groups they serve:

There's a sort've a lack of knowledge out there for some of the parents. A lot of them, sort've on the pill but didn't know that if you were sick that the pill didn't work, or if you took antibiotics, erm or so they told us, anyway, that they didn't know that. So, we just thought it would be a good idea to get somebody in that can tell them. RF, LARC professional: Social

Whereas others reflected that they might provide more information about LARC over others, or use LARC as the starting point when they consider this is most appropriate for the individual.

Everybody comes with their own experiences and history [...] If it's somebody that has a need that feels like a LARC would fit in there, then I'm going to be more likely to discuss it. If it's somebody who's been relying on condoms and we've seen them quite a few times in our service appointments before after emergency contraception then obviously they need something else. I mean I would discuss pills as well as LARC. DONNA, LARC Professional: Clinical

This idea of LARC being a superior method, or a superior method for particular users, can however produce pressure for service users to choose one (LARC) option. This arguably conflicts with FSRH standards to provide full information and support contraceptive choice from a full range of methods.<sup>57</sup>

LARC in the UK

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<sup>&</sup>lt;sup>56</sup> Broadhurst et al. (2015) <u>Vulnerable birth mothers and repeat losses of infants to public care: is targeted reproductive health</u> care ethically defensible?

<sup>&</sup>lt;sup>57</sup> FSRH (2016; 5) Service Standards for Sexual and Reproductive Healthcare

# Provider challenges

Notwithstanding differences in opinion about approaches to LARC provision, LARC professionals were united through their discussion about the challenges and complexity of supporting the "power of choice". As mentioned in the <a href="Background section">Background section</a>, the circumstances within which providers are being tasked to deliver LARC and other health and social support are increasingly strained:

I think sometimes, it's about quick things. Time constraints and time given to support people. I think that things like going to get the implant is a lot quicker to sort've support and have that conversation rather than a conversation about Choice and Where do I go, it's time constraints. I think a lot of services and for some services actually accessing LARC, is better than no contraception whatsoever. Sometimes I think it's seen as an easier option, it's an easier fix and it's an easier way of ensuring you know that a young person is safe. I think that we underestimate young people's power of choice, and that they will have things removed and they will have their own way of making a decision and choices. ROWENA, LARC Professional: Social

There are also the specific needs of each user to consider:

And many women do want LARC who've been in prison or whatever because they don't want to be in that situation again. But it's not right for everybody and it cannot be a blanket approach for everybody. People have to have choice. A free choice not 'well you can have this but ...', that's not a free choice. It's got to be a freedom of choice - give them the information and then they've got to make the decision. They know themselves far better than any clinician or social worker or whatever, they know what's right for them.

ALISON, LARC Professional: Clinical

Including the need to support the right to choose to try for a pregnancy that practitioners might consider unwise:

So for me, it's a fundamental human right — if a woman wants to get pregnant, that's her choice and when she wants to get pregnant that's her choice, as well. Obviously, as a worker I can see looking in that some times are better than others for women. But ultimately, it's her choice. I mean I can support her and get her to look at the pros and cons of when to get pregnant and all that sort of stuff, but ultimately, it's got to be her choice and I would say that we need to support women, whatever their decisions and whatever choice they make in terms of contraception or pregnancy. ADRIENNE, LARC Professional: Social

The approach described here by Adrienne with an emphasis on rights and choice, echoes to some extent the pillars of a Reproductive Justice framework. Reproductive Justice facilitates a holistic creation of services that *enable* individual choice through addressing wider *structural* factors e.g. lack of employment, education or training.<sup>58</sup> This sits in contrast to strategies that pay attention to addressing the individual (and their fertility) only.

We have demonstrated in this section about Non-Discrimination the ways in which different users' choices may be limited for example through stereotyping or ill-fitting resources for the individual (ethnicity, disability and so on). However, it is important to acknowledge the ways that LARC providers are also disadvantaged in this situation; namely by a complex negotiation around the perceived welfare of patients or service users, in the context of extremely limited resources and imperatives to cost-save.

<sup>&</sup>lt;sup>58</sup> Ross (2018) <u>Reproductive Justice as Intersectional Feminist Activism</u>

# Informed decision-making

This part of the report describes how LARC users perceive that services are failing to ensure informed decision-making in LARC provision. This includes that:

- Services fail to provide the information they require about available options, their risks and benefits.
- Provider practices and settings create pressure to choose LARC as the 'best' method.
- Provider practices and settings create pressure to delay removal of an implant, IUD or IUS.

Finally, it will look at the pressures faced by LARC Professionals about how they should deliver LARC.

### Informed decision-making means:

- having information that you understand about the full range of contraception options and their benefits and risks;
- feeling able to:
  - o choose the method that you prefer,
  - o refuse methods you don't want to use.
  - o stop using a method if you change your mind;
- making your own decisions without pressure from anyone else.

### LARC User Perspectives

I was told 'it's the best choice for you.' Well I believe MY choice is best for me. **Anon, 28, Survey** 

# Missing information on risks & benefits

Many LARC users considered that they had not received the information they required about their contraception options and their relative risks and benefits. The lack of information, and at times misinformation, compromised users' ability to make an informed decision consenting to contraception use. The key information issues perceived by users were:

- Lack of pre-contraception counselling on side effects including the perception that providers were withholding information about fitting or removal (e.g. the extent of possible pain experienced, scarring, or visibility of implant);
- Incomplete and conflicting information about side-effects;
- limited time to receive and consider information in appointments;
- limited method options explained or offered;
- overemphasis of favourable information about certain methods;
- no or incomplete information about methods' risks, side effects and possible noncontraception benefits (e.g. bleeding regulation or amenorrhea);

- withholding other information (e.g. having to use a larger IUD size when smaller unavailable, differences between different method brands);
- incorrect information about unsuitability of IUD and IUS due to age or parity (e.g. too young to use or only appropriate for users who have previously given birth);
- unrealistic picture of ease of removal (e.g. emphasis on the ideal of 'removal at any time you like', in contrast to the experienced reality of limited appointments and provider reluctance to remove); and
- inaccurate information about removal (e.g. stating there is a minimum time before removal is permitted, or that removal must take place at same location as the fitting).

Participants described how they felt they had received little information on the benefits and risks of a chosen option.

Because the woman who gave me it, didn't actually sit down and like give it me. You know like when you get a leaflet. She didn't even give me none of that. It was just literally I give you it today, give another 3 months, write this date down and just pre-book. They didn't tell me nothing. They didn't tell me that it would put, gain weight on you or you can lose weight. They didn't tell me nothing. Had to find it out myself by my mum. COCO, 19, Interview

I don't think the side effects are fully explained. They concentrate on the positives. I've also used the depo injection, and had to have a bone density scan. This was not explained to me as a risk prior to starting the injections.

Anon, 36, Survey

Others, said that their provider only explained what to expect from a method once they had proceeded with LARC insertion: "I wasn't given any information til I had it in my arm." (Anna, 29). This meant that users could feel unprepared (and alarmed) for side-effects later experienced:

I don't remember getting much information, probably because I was young and I was new to it, just sort've took it as that. And carried on getting it and then realised that, you know, like I could lose a lot of hair and then I looked it up and it said it can cause hair loss and stuff. So I stopped having it. PAMELA, 29, Interview

In contrast, positive experiences were reported when providers took time to share information on their contraception options:

Oh yeah it wasn't, they were really good like when I went to the appointment like they talked to me through what they were going to do and showed me it and all that kind of stuff[...]so I'm quite lucky like at my GP surgery they take time to talk to you about contraception and like what stage of life you're at,

# what form of contraception would work best for you and that kind of thing. SARAH, 31, Interview

This is consistent with guidance that indicates users are more likely to adhere to a method if they feel they have been adequately counselled and are aware of what to expect.<sup>59</sup>

#### Pressure to choose LARC

It is clear that many people felt pressure to choose LARC over other methods. We heard repeated accounts of pressure experiences across the workshop, interviews and survey: of people describing how they were "forced", "pushed", "pushed heavily", "urged", "bullied", "pressured" and "strongly encouraged".<sup>60</sup>

Of the 905/983 survey respondents who answered the question about pressure, only 50% felt able to state definitively 'no', they had never felt any pressure to use LARC methods.<sup>61</sup> 43.8% answered definitively 'yes' that they had felt pressure to use LARC with the remainder unsure or preferring not to say. LARC User participants from the survey, interviews and workshop combined perceived a number of concerning practices that left users feeling pressure to use LARC including:

- LARC methods positioned as superior to all other methods.
- Methods presented as the 'best', 'only viable', 'only sensible' or 'responsible' option for a particular user.
- Repeated efforts to encourage a switch from another preferred method (e.g. pill) to a LARC method, or between LARC methods.
- Repeated efforts to 'sell' LARC alternatives when a user has said they are not interested.
- Use of health concerns to insist on LARC method use as the only safe or acceptable option for a user.
- Use of a user's identity characteristics, most commonly young age or parity, to either insist on a LARC method or refuse another method.
- Evidence of previous contraception error e.g. emergency contraception use and abortion to encourage or insist LARC methods as a more 'responsible' option for the user.
- Leverage of setting leading to rushed decision-making e.g. limited time in appointment, or prospect of difficulty of obtaining a new appointment if want to try at later date.

<sup>&</sup>lt;sup>59</sup> See for example FSRH (2019; 5) <u>Contraceptive Choices for Young People</u>

<sup>&</sup>lt;sup>60</sup> Verbatim words that were used repeatedly by LARC user participants across survey, interviews and workshop.

<sup>61 905/983</sup> respondents answered this question.

# LARC as 'the best' option

Providers' enthusiasm for LARC options was one of the factors that created pressure to opt for LARC. Counselling styles defined in wider literature as 'directive' or 'LARC first,'62 were described frequently by our LARC user participants:

The doctor at sexual health clinic immediately told me he would like me to use LARC before asking me any questions. When I asked for the POP, he again said he would prefer to give me the injection or implant with the same hormones. When I said I'd like to try the pill first to see how I get on, he told me that it wouldn't make a difference as they are all different. I had to really stand my ground to get the pill version. Anon, 24, Survey

Many described providers akin to salespeople: "It was like sold to me as the best thing ever" (Anna, 29, Interview) that made repeated efforts to encourage a switch from their user-dependent method in current use (often the pill) to a LARC option, or between LARC methods (often the injection to an implant or coil):

Every time I've changed contraception method (whether I've been looking for something completely new or a different brand of pill) all conversations led to the Mirena. This was with my GP, with various doctors at my local sexual health clinic, and midwives and nurses that I spoke with following my abortion during a conversation where they wanted me to make an immediate contraception decision. Every time felt like a Mirena sales pitch. I eventually decided to get one and do think it was my best contraception option but it felt like healthcare professionals are very heavily encouraged to get women on the Mirena. Anon, 23, Survey

Others felt that a provider would be pleased by their decision to use LARC: "they were not pushing but it felt you know that's what they sort of wanted you to do," (Lucy, 30, Interview); or unhappy with them for declining LARC options:

I went to my GP for help with heavy and painful periods. He recommended the Mirena coil several times over the course of 4 appointments and was quite insistent that it was a good option. I'd previously had bad experiences with the copper coil and the pill so refused to try it. He eventually prescribed medication but was clearly unhappy with me. Anon, 40, Survey

<sup>&</sup>lt;sup>62</sup> Gomez et al. (2014) Women or LARC First? Reproductive Autonomy and the Promotion of Long-Acting Reversible Contraceptive Methods; Higgins (2014) Celebration meets caution: LARC's boons, potential busts and the benefits of a reproductive approach

Some talked about feeling like the practitioners had greater "power," "tools", and "information" to lead their contraception decision.

You know, they have the tools, so they were going to be able to just, you know, I think THEY decided what the preferred method was and I didn't really understand why. But I just felt that they were the experts, so I couldn't' **ZOE**, 31, Interview

At this point I didn't actually have any information that I could fight my own corner about, part from that's not what I choose, I don't feel comfortable with this. ... And I felt that she should be giving me that information and those options rather than just telling me what she wanted me to do. LAUREN, 30, Interview

Best practice contraceptive counselling strikes a comprehensive balance between delivering good quality medical information and empowering the patient to make their own decision (even if the medical professionals feels this choice is unwise).<sup>63</sup> Many examples given by our participants did not demonstrate this balance.

# The best decision for you

For other LARC Users, pressure was perceived from a provider's emphasis on one method as the best or only contraceptive option for them. Whilst providers may have sought to emphasise the additional benefits of some LARC such as the Mirena IUS in treating endometriosis and heavy menstrual bleeding (HMB), users could feel that their providers were excluding other options:

So the three options I was presented with they were what I gather now I'm older, that the midwife felt they were the best decisions FOR ME. And so I felt like that choice was not entirely mine. NIA, 29, Interview

Some described providers citing their identity characteristics explicitly, most commonly their age, to encourage a specific LARC method or to suggest that they were better-placed to decide on the user's behalf:

I was pressured as a teenager into getting the copper coil as a teenager because I was told it was 'hard to remember to take a pill everyday'. Anon, 28, Survey

<sup>&</sup>lt;sup>63</sup> FSRH (2018) FSRH Service Standards on Obtaining Valid Consent in SRH Services

Yeh, I felt like, erm, also I was very young at the time, but I felt like[...] I wasn't trusted as an adult to make the right decisions myself. Perhaps my disability was taken into account as well. This is just a guess but how I've experienced life tells me that (SIGH) I was talked to as if they were the ones to make the right decision. NIA, 29, Interview

Others felt guilty, embarrassed, or irresponsible for their contraception needs, including as a consequence of their sexual life:

That experience was really, really bad because it was just like the doctor pretty much being like 'you're really promiscuous' and like 'we need something that will pretty much control this slight promiscuity, so take this because nothing else will work. Dee, 20, WORKSHOP

The pressure experienced often related to a user's experience of abortion. One participant described how she felt a provider was "almost extra keen" to insert an IUD as emergency contraception because she had had a previous abortion. Similar pressure was reported in relation to seeking emergency contraception:

And the pharmacist said to me: 'if you're going to forget to take your contraception you really need to be on a type of contraception that you'll remember.' He was like 'it's not ok to be reckless.' I felt really embarrassed and I felt like I was making the right and responsible choice in the situation that I was in and I was made to feel really ashamed for that. And that just wasn't very comfortable and he kind've spent the whole time sort've, like 'I really think that you should get the coil, I think the coil is the best decision'. And it was really insulting because it was a man I'd met for 5 minutes, and I was thinking 'you don't know me at all'. AIMEE, 27, Interview

Some participants shared how their providers 'used' a clinical issue, such as a higher Body Mass Index (BMI), experience of irregular bleeding, history of migraine, suspected endometriosis or adenomyosis, to insist on LARC. They described feeling like they did not have a choice or did not have the information to understand this balance for themselves:

Well the whole thing was just effectively about how fat I am. From start to finish her answer to almost everything was 'well you have a really high BMI'. LAUREN, 30, Interview

So I was very disappointed that you know when I was being told when I say it wasn't a choice, the IUS, because I literally was sitting there saying: I do not want hormones I do not want hormones but I had to because[...]they say it prevents — I still get the pain, not to the same extent but I still have a lot of pain. But that's the one that should reduce it. **Kelly, 25, Workshop** 

I have suspected endometriosis. I was advised to try Mirena to relieve the pain, but it was presented to me as essentially the only option, so I felt like I had no choice but to say yes. **Anon, 28, Survey** 

Of course, some conditions present a legitimate clinical contraindication to a particular contraceptive method. This evidence however indicates that some health care professionals may need to ensure that users understand the distinction between whether their medical condition is a contraindication for method use, or if another method may simply confer additional benefits.

# 'High Risk' users

Patients that have chronic conditions such as epilepsy or acne are often placed on medications such as Sodium Valproate or Roaccutane which are known to cause foetal abnormalities and are hence subject to 'pregnancy prevention programmes'.<sup>64</sup> For this reason, users of these pharmaceuticals are often counselled to use LARC methods so that it is extremely unlikely they will have an unplanned pregnancy.<sup>65</sup> However, some patients described feeling harassed into using LARC methods and having to enter into a 'contract'.

Sarah, 31, uses sodium valproate as part of her epilepsy treatment and has been required to follow a Pregnancy Prevention Programme following the guidelines released in 2018.<sup>66</sup> In partnership with her GP nurse, Sarah decided that she would like to continue with her own preferred method (the contraception pill) rather than moving to the provider's preferred LARC. Sarah shared how the 'contract' she had to sign to accept responsibility for her contraceptive decision could be upsetting and could feel like being 'forced' to use contraception:

I think because of the way it's presented, it's literally like a contract. Because you have to tick it and sign it and if you're under 18 you have to have a guardian sign it. And it doesn't feel like it's your choice to be on contraception. It feels like they're telling you that you have to be. And even me who was on a long-term contraception, I was questioned as to why I

<sup>&</sup>lt;sup>64</sup> Medicines & Healthcare products Regulatory Agency (2020) <u>Valproate use by women and girls</u>; and Roche (2016) Roaccutane®: Pregnancy Prevention Programme

<sup>&</sup>lt;sup>65</sup> Although LARC are considered most effective due to their reduced scope for user error, other effective user-dependent methods would also support pregnancy prevention (if used in 'compliance' with prescriber guidelines)

<sup>66</sup> Gov.uk (2018) Valproate Pregnancy Prevention Programme: actions required now from GPs, specialists, and dispensers

wasn't on one of their chosen methods. Which I felt like a little bit like, I was so, I've done my research, I have a good relationship with my nurse at my GP surgery. This is the contraception that we've decided together is best for me and my situation. I didn't really understand why it needed to be questioned. But I think they are happier with people being on the longer-term stuff.

SARAH, 31, Interview

Others spoke positively of their providers' efforts to offer clear, informed contraceptive counselling and to explain the health risks to themselves or a foetus in the event of an unintended pregnancy, especially as many might not have access to the *right* information in on risk in the first instance:

So yeah yeah I've never felt pressure really. I just felt they've given me information about what would be best for me and my epilepsy and family planning. And I think that's good. Yes because lots of people don't get the correct information and you could get things that would interfere with either epilepsy or their family planning. CLARE, 42, Interview

Less frequently, participants described pressure *not* to choose LARC methods. Overlapping with earlier findings in the Non-Discrimination section about who counts as an 'ideal mother' and at what life stage, providers in some examples discouraged users who wanted to try an IUD or IUS because of their (young) age or because they had not had children:

GP would not give me one as I hadn't had children yet - eventually had to pay privately to see a gynaecologist in order to get an IUS. Anon, 31, SURVEY

This is consistent with wider evidence that indicates that some clinicians perpetuate 'out of date' information about the clinical suitability of IUD and IUS methods for young or nulliparous users.<sup>67</sup>

# Time and place to decide

Recent findings suggest that many women are struggling to access postpartum contraception,<sup>68</sup> explained in part by the disjointed commissioning structure of sexual and reproductive health services in the UK. Inevitably the resulting unintended pregnancy and requirement for abortion is placing a huge burden on people during their already challenging postpartum period. By contrast in our research we heard from some LARC Users who have experienced pressure to engage in contraceptive counselling 'too soon' for them in the

<sup>&</sup>lt;sup>67</sup> Daniele et al. (2018) <u>Provider and lay perspectives on intra-uterine</u> contraception: a global review

<sup>&</sup>lt;sup>68</sup> APPG SRH (2020) Women's Lives, Women's Rights: Full Report

postpartum period when they were feeling harassed and struggling to decide about their contraceptive preference<sup>69</sup>:

I think they talk about what your plans are too much. I think in that way you sort've feel pressured. 'What do you want to do after you've had your baby? As soon as you've had the baby we can put a coil in or give you an injection'. I'm not even halfway through my pregnancy yet. I don't even know if I want drugs when I give birth, let along think about what's going to come after. Because after you give birth your head's all over the place. I don't think that's any time to decide what you should be putting into your body for the next 5 to 10 years. RACHEL, 28, Interview

In abortion care, we heard similar stories of people finding it difficult to make their own contraception decision in what could be a rushed or emotional environment. Some described feeling pressure to agree because they felt grateful to have received the care they needed:

I was so upset by what I was going through. It was really hard. It was really hard to decide to have an abortion. It wasn't what I wanted to do. So that was a really hard decision and I just wasn't in a state of mind to make an informed decision about a lot of other things...like having an implant, what contraception I wanted after. I wasn't ready to think about after. I kind've just wanted a couple of weeks after to get myself together and then start thinking about things like that, start thinking about the future. ANNA, 29, Interview

Whilst others described their experiences in starker terms: 'After I had an abortion I was basically forced to have an implant by the nurse' **Anon, 36,**Survey

In addition, the scarcity of contraceptive appointments, meant many survey respondents particularly reported feeling rushed to decide and 'grab the opportunity' whilst it was available. What these accounts do best is highlight the importance of correct timing in contraceptive counselling and the resource in contraceptive services which allow for discussions and a 'cooling off' period in order to ensure consent is fully informed.<sup>70</sup>

<sup>70</sup> FSRH (2018) FSRH Service Standards on Obtaining Valid Consent in SRH Services

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<sup>&</sup>lt;sup>69</sup> This is an important contrast to existing evidence about challenges in accessing all contraception postpartum at the current time. This may be explained as follows: i) the project had specific objectives to explore 'LARC and pressure' and therefore the respondents had experiences that speak to this theme; ii) we do not know the specific dates of the postpartum experience in question for our participants i.e. they may have been reflecting on their experience from some time ago. However, we wanted to include these perspectives to honour the experience of our participants and also to provide an example of how the timing and context can matter in decision making about LARC.

# Pressure to delay removal

We heard accounts from LARC users that suggest LARC users in the UK are routinely pressured to delay the removal of a LARC method. In our online survey, 54% of total respondents (983) confirmed they had wanted to have a LARC removed at some point. Of these, 56% (n=296) expressed that they experienced difficulty in arranging removal. People described having to "beg", "really push", "convince", "fight" and "stand one's ground" to implement their removal decision. The delay between an initial request and the removal ranged from six weeks to six months. In between, users described frustration at being required to return for multiple appointments, travel to other clinics and chase providers for 'approval' of their decision. Challenges included:

- Perception that providers were 'manipulating' available appointments to achieve delay in removal.
- Emphasis on perseverance with side-effects and insistence on allowing method to 'settle in'.
- Use of cost (to the NHS) and scarcity of LARC to encourage continued use.
- Suggesting a minimum timeframe for LARC use before provider would be willing to remove e.g. will only fit if understand will not remove before six months.
- Dismissing concerns with method, not taking seriously experiences of side-effects.
- Use of other health issues to avoid removal e.g. perceived mood impacts were related to mental health problems not contraception.
- Attempts to dissuade from removal because of judgement that not reliable to take other user-dependent methods or because the person should not get pregnant at this time
- Prescription of other medication to 'treat' unwanted effects such as bleeding irregularities, despite removal being user's preference.
- Demand for users to provide 'legitimate' reasons for removal.
- Direct refusal to remove.

#### Valid reasons for removal

Access issues were particularly pronounced for removal and will be discussed in further detail in the final <u>Accessibility section</u> specifically. Limitations to access interplay with informed consent whereby fewer providers are trained to remove LARC than insert, services are offering fewer drop-in services for removal than insertion, and by default users are forced to continue an unwanted method in the interim period. Again, these resource implications may unintendedly create pressure as providers may be inclined to dissuade users from removal by various means. Whilst some users found it informative to hear about what side effects to expect and how this might change over the course of a method, others felt this meant they were expected to persevere with the method regardless of their own preferences and experience. This expectation would exert varying degrees of pressure to continue with a method and allow it to "settle in":

She was just like: 'OK, well if you really really need to then you can come back' but I think I'd made up my mind that if I did experience certain symptoms I would probably go for about 6 months. NIKKI, 30, Interview

A small number of participants were told explicitly that they would not be allowed to remove the LARC method during a specified time period – three or six months. For users who wanted LARC removed due to irregular bleeding many described how providers favoured the prescription of the contraceptive pill (in addition to their LARC method) to regulate the bleeding over 'agreeing' to their removal request.

It was an absolute nightmare waiting to get it removed and they were so reluctant to have it removed, cos you know she said it was a good form of contraception, obviously all the bleeding they were trying to give me additional pills and it was just like: 'no I just want it out now, I've had enough.'

LUCY, 30, Interview

Whilst FSRH guidance on problematic bleeding due to LARC suggest that this side effect may settle over a period of 3 months<sup>71</sup>; our evidence from LARC users suggests that this instruction appears to be misused, poorly explained or disregarded by some health care professionals:

I think women should have more of a right of what goes in and out their body and they shouldn't have to fight to get something out their body they don't get on with. I hated the implant and I had 3 years of awful periods because of it and I was forced to suffer because they wouldn't let me have it out Anon,

19, Survey

People perceived that providers failed to hear or take seriously their concerns with a method-further reflection of the disconnect between the priorities of LARC users and LARC providers respectively who value different aspects of LARC and frequently misalign on what needs to be 'taken seriously.' Whilst LARC are the most effective method for preventing unintended pregnancy users often felt that other considerations e.g. about their dislike of 'foreign bodies' or hormonal disruption were not being listened to. This meant that many LARC users in our research felt amongst other things: patronised, dismissed, minimised, disbelieved and that they were considered to be melodramatic, irrational, or like they were 'making things' up. Sometimes users resorting to lying to give the provider a 'valid' reason for the removal request, such as being in a 'same-sex' relationship or wanting to conceive.

Refusal to remove a method until a user had booked an appointment for the next insertion, or agreed to a new contraception plan was reported. Some LARC users reported their

<sup>&</sup>lt;sup>71</sup> FSRH (2015) FSRH Clinical Guideline: Problematic Bleeding with Hormonal Contraception

providers had refused or actively discouraged removal even when the user wanted to conceive:

When I was younger I found that I had a lot of problems and I was trying to ask to get my implant removed. People were thinking that because I was 20 years old, 19 or 20, they felt they should talk me into keeping it and not having children, so it was I guess about 6 months the first time before I was at the family planning clinic. Yes, it was about 6 months before I could talk them into removing it the first time. TANITH, 32, Interview

As a result of the failures to respond to their requests, many LARC users expressed that they would avoid LARC in the future and instead opt for user-dependent methods like the pill where they were "in control a bit more" and could stop at any time. Therefore, efforts by providers to encourage sustained use against the wishes of the user not only infringe upon informed consent, but compromise the desirability of LARC. The 'reputation' as 'difficult to remove' meant some LARC user participants were put off after hearing friends and family describe their challenges, before they had even used LARC themselves.

Users were also (made) aware of the cost of a LARC method, that they are scarce and that they therefore need to last. For some this meant delaying their own removal request despite experiencing unacceptable side effects. Robin, 22, explained "I just feel, I would feel guilty, going back and getting it out"- a theme which may reflect the ways that wider 'social pressure' e.g. from news media coverage about the 'responsibility to protect the NHS,' may also shape (informed) decision making. However, some LARC users also reported direct pressure of this nature from their providers:

I was told they were reluctant to remove it as implants are expensive and to keep giving it longer amounts of time to see if the side effects stopped, had to ask 3 times for it to be removed. Also, was told had to be removed at location it was placed even though I had moved away from area. Anon, 24

Survey

However, no-one is arguably more aware of the cost imperatives related to LARC than LARC providers themselves. We also heard these accounts through our LARC Professional interviews, as described next.

## LARC Professional Perspectives

And that's my worry professionally because contraception has got to be the woman's right to choose, to have it or not to have it at all - that's up to her.

And it's really hard to get that balance right. Helen, LARC Professional:

Clinical

## Targets, enthusiasm and pressure to choose

In recent years, a number of cost calculators<sup>72</sup> have been produced to highlight the benefit of providing LARC methods in relation to the impacts of unintended pregnancy. In a mirror of the experience of LARC users, some LARC Professionals discussed how they felt these cost saving pressures in their practice could, in turn, impact user experiences of pressure to choose LARC methods. Providers indicated it could be challenging to navigate the sector's enthusiasm for LARC and ensure access to LARC whilst protecting users' choices.

LARC Professionals recounted the impact of both commissioning expectations - key performance indicators, that were part of their contractual arrangements and by default necessary to deliver, especially to ensure the retention of their core funding:

They [commissioners] would like 30-40% of the women that we treat leaving with a LARC. Whether that be a coil or an implant[...]so they would to see that amount of women who've been treated with us leaving with that form of contraception[...] That's like an example of a KPI. Which is fairly standard across the board. Kirsty, LARC Professional: Clinical

Some practitioners worried about unintended consequences i.e. that KPIs could lead to teams being "over enthusiastic" about LARC and, consistent with the perceptions of LARC Users, preoccupied with trying to be a "good salesperson" for these favoured methods. They talked about targets on a staff board, league tables, a shared cultural understanding that "LARC is best".

This presented a risk of skewing the focus towards particular methods, in particular Depo-Provera because it 'counted' as a LARC "without needing to invest the time and the staff training and the appointment resources to actually fit implants or coils." The same LARC Professional described how at one point, the initial telephone consultation for an early medical abortion had involved healthcare assistants offering Depo-Provera as an "opt-out option" and that for LARC providers it is "second nature" to recommend them:

I guess every training course you go on is all about how can we promote more LARC and get more LARC into people. Generally, LARC are considered a good thing by all people involved in sexual and public health. And definitely the awareness of that permeates all the services. I guess I've been working at it so long now it's difficult ... it's just kind've that knowledge that all the services have. DONNA, LARC Professional: Clinical

Some providers worried that this could lead their colleagues to overlook a patient's individual preferences. Helen, LARC Professional: Clinical described the risk of "bustling them [USERS] into it" — "you know, 'this is great' bla bla bla and not kind've hearing any kind've doubt that the woman might be expressing." The focus could also lead to an

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<sup>&</sup>lt;sup>72</sup> PHE (2018) Contraception: Economic Analysis Estimation of the Return on Investment (ROI) for publicly funded contraception in England; Bayer (2018) Budget impact cost calculator

assumption that services would prioritise LARC uptake. Sharon, LARC Professional: Clinical described her experience establishing a contraception service in a prison:

But it was interesting because everyone thought that my main role was there just to bang a LARC in. And that's a word that they use. 'You're going to bang a LARC in are you?' And I said: 'no, I'm here to educate and inform women of their choices. And if they choose not to have something, that's absolutely fine.' SHARON. LARC Professional: Clinical

Sharon recalled publication of the 2005 NICE document:

About how much money the NHS can save if women had a LARC [...] That's years ago and there's always been that push, I think everywhere to try and get people on a LARC; it's better for the NHS; it'll save money; it's better for the woman. SHARON, LARC Professional: Clinical

And the resulting strategies to push back against any pressure to focus on LARC:

But whenever I go and see commissioners I always say to them: it's about choice and you have to remember that women choose, and you can't put a target, you can't really put a target on it because, you know, it's not right. And when you talk to them and tell them they do understand and I think our business team are quite good at doing that, and standing up to them and saying: no, that's not right. Because I will always turn it round to them and say: so how would you feel if somebody said to you, you've got to have a LARC. SHARON, LARC Professional: Clinical

Other providers pointed to the many protections *against* coercion. They explained that contraception and sexual health professionals, particularly in abortion services, are skilled at "picking up ambivalence" and taking full consent. Simon, LARC Professional: Clinical/Academic suggested, consistent with current evidence about access limitations, 73 that GPs "barely break even" on LARC fittings and removals, there is little reason to push someone towards a LARC option:

I would spend a lot more time talking about options if people are genuinely ambivalent, so I wouldn't push them to have a LARC, when there's no urgency involved because there really isn't that much in it for me to, you know I have to go through the bother of making an appointment and all that sort of stuff, but it's about: is it suitable, is it a genuine option and the woman really wants

<sup>&</sup>lt;sup>73</sup> APPG SRH (2020) Women's Lives, Women's Rights: Full Report

# it, then that's what I have to do. SIMON, LARC Professional: Clinical/Academic

Interviews with LARC Professionals suggested a need for critical conversations within the sector about how to balance an individual's choice and wider social benefit in the role of contraception provision. Some Professionals reflected that the current framework of LARC provision frequently poses a conflict between the two. One of the strategies to manage this situation involves up-skilling in contraception counselling, ensuring a user has the information they need without feeling pressure to choose a particular option. This is contingent on providers' training and understanding of LARC methods, discussed next in more detail.

#### Gains in LARC awareness and access

LARC Professionals identified that LARC policy changes, such as the 2005 NICE guidelines and 2009-2019 Quality and Outcome Framework indicators, helped to improve provider awareness of the methods and thus enhance the information users received about the range of contraception options:

When I give seminars, workshops and things there's still prevalent old-fashioned views about: 'oh, you shouldn't fit IUDs in women who've never had children' or you know, the under-20 whatever at risk of Chlamydia.' So there were a lot of these views — I mean they weren't very prevalent. Sometimes, it's just even one. And then one patient hears it from you, and then that's their view for a long time, until they hear something different. SIMON, LARC Professional: Clinical/Academic

So it's sort of breaking those myths really which I think is happening. More and more sort of mid-twenties young women are coming in and saying 'I am fed up with hormones, I don't want to get pregnant just yet I'd like something without hormones so I'm really interested in the copper coil'. And I go like 'ok let's do that'. RACHEL, LARC Professional: Clinical/Academic

We have heard already in the <u>Non-Discrimination section</u> about the value and pitfalls of targeted or enhanced LARC care to counter the many difficulties of access for some population groups. LARC Professionals shared how improving contraception options, including LARC options, in contexts like post-partum care and family support services can offer real and important benefits to service users. However, at the same time, mirroring findings from the LARC users, LARC Professionals were aware of how some contexts might not feel "benign" to users:

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<sup>&</sup>lt;sup>74</sup> The Quality and Outcome Framework or 'QOF' is a "pay-for-performance programme, implemented in April 2004 by the National Health Services (NHS), [that] linked GP income to performance against targets set in QOF indicators": Myat E. Arrowsmith and others, 'Impact of Pay for Performance on Prescribing of Long-Acting Reversible Contraception in Primary Care: An Interrupted Time Series Study' (2014) 9 PLoS ONE 1. From 2009 to 2019, the Framework included indicators for contraception focused on monitoring particular prescriptions and facilitating the uptake of LARC. See: The NHS Information Centre for Health and Social Care, Quality and Outcomes Framework Achievement Data 2009/2010 (2010, NHS) 4

We've driven a contraceptive nurse up to the day programme where people are having a child protection assessment, and we note whether or not they take up the offer. You know, and to some extent, people will have a view on whether or not the offer was accepted. It's not a benign environment, is it?

LYNN, LARC Professional: Social

#### LARC Removal

On LARC method removal, some LARC professionals shared their own perspectives on how and why they might encourage users to let a method "settle" (as described by LARC users). Janet, a nurse in abortion services, told us how sometimes users may not "take on board that it's worth sticking with [a LARC method] despite early irregular bleeding"; and that it could be important to advise a client on the benefits of waiting for a short period to see if side effects may improve: "Not say: "it doesn't matter that you're bleeding" because clearly it does. But there are ways it can be managed."

But others expressed concerns that wait times could be used "as an excuse not to take things out when people want them to" Donna, LARC Professional: Clinical; a circumstance that would depend on the practitioner:

It might come from the judgement of the practitioner who would then put them into a clinic, a specific clinic. Depending on the next available appointment it might just be the following week. It could equally be 3 months' time. Whereas I would just do it there and then - Take out an implant, just takes seconds. I've just been a bit at war with my colleagues. Everybody comes from a different place don't they. RACHEL, LARC Professional: Clinical/Academic

In a way that may help improve the 'reputation' of LARC and control for users, LARC Professionals may explain the potential removal difficulties when helping users choose which method was best for them e.g. advise against LARC if they valued control. Some also reflected an explicit rights-based approach to LARC removal:

And if somebody wants it out, you take it out. You know, forcing somebody to leave it in by refusing to remove it [...] it's forcing somebody to take a medication that they don't want to be taking any more. That's unacceptable in any other circumstances in healthcare so why would it be acceptable to refuse to remove a long-acting method? DONNA, LARC Professional:

Clinical



# **Accessibility**

This part of the report outlines how people experienced difficulty accessing LARC services. It shares examples of how:

- Users face practical barriers to start, stop and renew LARC methods.
- Users struggle to ask questions, obtain information and openly discuss their contraception needs with providers.
- Services fail to ensure users are able to choose from a full range of contraception options.

#### Accessibility means

- Being able to find or receive information that you understand about your contraception options.
- Being able to access the services you need in your local area within a reasonable time.
- Having venues, signs and equipment that are appropriate for your physical needs.
- Being able to choose the best method of contraception for you from the full range of options.

# LARC User Perspectives

Accessing the resources isn't easy when there's 4 weeks wait for appointments and 4 hour wait at walk in appointments **Anon, 24, Survey** 

# Barriers to start, stop and renew LARC methods

Contraceptive services are stretched. As we discussed in the <u>Background</u>, for several years services and advocates have warned of unprecedented pressure from fragmented commissioning and year-on-year funding cuts.<sup>75</sup> In the final section we present accounts direct from the perspective of LARC users that bolsters this existing evidence about service access problems. Many LARC users, especially those who took part in the survey, explained that they had wanted to start, renew, or remove a LARC but faced barriers to the care they needed. Key barriers identified were:

- long waiting times for next appointment (from 2 weeks to 9 months);
- limited clinic opening hours, often incompatible with participants' caring, work and study responsibilities;
- delays and waiting times at walk in centres (needing a full morning or day free to visit);

<sup>&</sup>lt;sup>75</sup> Advisory Group on Contraception, *Cuts, Closures and Contraception: An audit of local contraceptive services in England* (November 2017); Royal College of General Practitioners, *Sexual and Reproductive Health: Time to Act* (RCGP, 2017), accessed 24 June 2020, <a href="https://www.rcgp.org.uk/policy/rcgp-policy-areas/maternity-care.aspx">https://www.rcgp.org.uk/policy/rcgp-policy-areas/maternity-care.aspx</a>. APPG SRH (2020) *Women's Lives, Women's Rights: Full Report* 

- limited sites that can provide LARC methods involving long travel times and difficult or expensive transport connections;
- service providers not trained to fit all methods, particularly in GP setting;
- need for multiple appointments to allow time to consider LARC choice despite some users having undertaken extensive research beforehand to decide upon their method;
- need for multiple appointments to align with other 'clinically relevant' factors such as STI testing and results, pregnancy testing, timing with menstrual cycle;
- lack of up to date information and signposting by services e.g. GPs not knowing where best to direct people wanting to use a LARC method;
- requirement to collect own prescription for implant/IUD to take to fitting appointment;
- age limits on services that restrict access especially for users over 25 years of age;
- change in available services during life of a LARC method (e.g. moving between local authorities, individuals 'ageing out' of youth services, services closing, trained staff leaving GP);
- lack of appropriate equipment to meet physical needs (e.g. beds unable to be lowered for wheelchair users seeking fitting); and
- total suspension of services during COVID-19.

All of these circumstances related to access have certainly been exacerbated by the onset of COVID-19 and lockdown restrictions which meant several LARC clinics were postponed or services closed, delaying and disrupting removal and replacement of LARC.<sup>76</sup> This is despite the WHO's emphasis that continued provision of Sexual & Reproductive Health (SRH) services is an essential aspect of health care. 77 A circumstance which is further perplexing when the cost-effectiveness of LARC methods and the return on investment is so widely acknowledged.<sup>78</sup>

# Fighting to be seen

We heard from LARC user participants how people were "constantly in battle" to access care and "fighting to be seen":

I was competing against every single person in my borough to get into kind of one space [...] So I kind of went onto the website and I knew that they released their slots every Tuesday and Friday so I had to kind of wake up early, keep refreshing the website and pray that I got an appointment. Number One. 25. Interview

<sup>&</sup>lt;sup>76</sup> APPG SRH (2020) Women's Lives, Women's Rights: Full Report

<sup>77</sup> WHO (2020) Maintaining essential health services: operational guidance for the COVID-19 context interim guidance 78 PHE (2018) Contraception: Economic Analysis Estimation of the Return on Investment (ROI) for publicly funded contraception in England

LARC users described waiting weeks and sometimes months for an appointment. For some these waits had become routine, were frustrating and could also be physically uncomfortable:

Especially with coils, they said that there's normally up to 3 weeks waiting anyway so to them, it was like this is normal. So stop like, stop complaining, cos they can't do anything. Like you wait [...] I had to wait for two and a half weeks and I was in a lot of pain and I was working in a café so it was really problematic cos I was having to stand up all day and things like this. Leah, 25, Interview

Albeit infrequently, some LARC users resorted to attempting to remove a LARC themselves:

My GP couldn't remove the implant so I had to go back to the clinic. The clinic would put in an implant any time they are open, but only take them out between 8 and 10 on a Wednesday morning. I attended 3 of these and every time they were already full - some girls were queuing outside from 6am to get a slot as only the first 8 in the queue could be seen for implant removal. I rang lots of different clinics and they all said they could only remove the implants that they themselves put in. I even tried a private GP but they couldn't do it either. I became so distressed that I couldn't get it removed even though I didn't want it in my body anymore that my mum and I tried to cut it out ourselves! We gave up because it hurt too much and then next week I went to the clinic hours before it opened and got a slot [...]I still have the scar on my arm where I tried to remove it myself, I've been on the pill Dianette ever since and will never try long term contraception again - I hate the thought of having something in my body that was doing me bad and I can't take it out. Anon, 22, Survey

Other than frustration and distress, waiting can pose particular problems in the context of time sensitive LARC methods e.g. the injection needs to be administered at specific times to ensure the user is 'covered' (their method has not expired):

One bad thing about being on the injection or anything, obviously you've got to go for renewing the injection in your bum. You've got to go to the doctor's to give you it. If you're due now and you can't get an appointment til next week, you're always a week behind. So you just think well what's the point?

COCO, 19, Interview

LARC users described going to great lengths to fit limited service options into their own lives. We heard of participants missing school, or taking annual leave after being unable to find appointment times to fit with their working hours. Many told us they would need a half-day or a full-day to be seen at a walk-in service:

I got there at 10.30 and was given a ticket, and then was told to come back at 2.30. So in actual fact, it's like the whole day's taken up just to get what you need implanted or taken out. Melissa, 30, Workshop

Limited appointments and uncertain waiting times posed problems for participants balancing the care of their children or other dependents. Some LARC user participants found it "almost impossible" to find childcare to attend a clinic as a single parent whilst another resorted to waiting in a queue for four hours with their young children. Limited options pose particular challenges for people experiencing socio-economic disadvantage and people with precarious work such as zero-hour contracts, or limited autonomy over their working lives- exacerbating health inequities.<sup>79</sup> Some participants were entirely unable to access the services they needed, a circumstance that could be influenced by where you live and transport access:

The place closest to where I live is an hour's bus journey away from my address and 40-minute train journey. Other options may be available in a more local facility, however not for the insertion of a copper coil or implant. They are also open for very limited time so finding time out of work in the appropriate hours to travel there would be almost impossible. Anon, 26, Survey

There was a family planning clinic in the town 30 miles away, but it only operated on a Tuesday night between 7 & 9 and a Thursday night between 7 & 9. Only I lived out in the country 30 miles away, and buses aren't that frequent, especially after 5 o'clock at night. You would have had no hope of getting a bus at the time to attend an appointment so it cut you off from it.

TANITH. 32. Interview

Consequently, some chose to switch *from* a preferred LARC to overcome the struggles with appointments. Naturally, time delays to secure methods also led to unintended pregnancy:

I tried to arrange it via local GP practice. it took a long time for me to be able to register, there was another wait to see a GP, and another wait for a letter informing me she couldn't fit the coil and directed me to a sexual health clinic. By this point I had already arranged an appointment at a sexual health clinic, but when I went there I was told I was 5 weeks pregnant. Anon, 32, Survey

## No time to decide

On the flip side of long waiting times to access LARC in the first instance, there are other timing challenges when users get into the service. In order to obtain valid consent, the FSRH

<sup>&</sup>lt;sup>79</sup> APPG SRH (2020) Women's Lives, Women's Rights: Full Report

explicitly identifies that people should 'have received sufficient information to make the decision along with time to reflect and an opportunity for discussion.<sup>80'</sup> Many of our participants however described that they found it difficult to obtain the information they needed in the time-frame of the appointment:

It was quite a rushed appointment because there were so many people there [...] I didn't really feel like I had time to sit and talk, you know, about it before I had it. ... I didn't feel like I could approach them because of how quickly they were getting people in and out. Nia, 29, Interview

These time limits mean that users may struggle to access their preferred method in the first instance, whilst simultaneously rushed appointments may mean that full informed consent may be compromised:

I can't really explain to you. You had to be in that room. They didn't actually say 'are there any questions?' they didn't, they just said 'you're finished now'. I'll see you in 3 months time. And you think why can't I give you any questions. It was like [...] 'I give you this and you're finished. Don't worry till 3 months' time'. COCO, 19, Interview

A circumstance that was called out (directly and otherwise) as 'unfair':

It's unfair for a health professional to only give you one option when it comes to contraception. Honestly, I feel like GPs get frustrated when you want to discuss your contraceptive options as they have a limited time slot with you.

Anon, 29, Survey

To remedy this, many users find their own information online or through waiting room leaflets. Some talked about the benefits of hearing about real people's experiences on platforms like Reddit and YouTube. This had the added benefit of allowing users to get on an "even footing" with their provider and offering some sort of empowerment:

I just love being able to read and find out stuff for myself, rather than just rely on everyone else. Robin, 22, Interview

To respond to this 'gap' in time for conversation and trustworthiness of resources, there are ever growing online sexual and reproductive health resources, albeit some more reliable than others. Whilst consultation of 'Dr Google' is fraught with pitfalls relating to the perceived reliability of information, efforts to provide good digital resources continue, as do attempts

<sup>&</sup>lt;sup>80</sup> FSRH (2018) Service Standards on Obtaining Valid Consent in Sexual and Reproductive Health Services

to improve user power and autonomy.<sup>81</sup> Indeed, self-removal of LARC methods is something that some patients are attempting<sup>82</sup> and globally 'DIY' activists offer advice and guidance 'informally.' <sup>83</sup>

# Limited availability of methods

Services seemingly failed to provide users with a full range of contraception options. Our accounts collected from LARC user participants underlined the importance of a full contraceptive menu to respond to the different things that individual users value in a method. This, like sufficient time and information, is consistent with best practice guidelines that identify that to maximise acceptability 'the full range of methods should be available' and this should include diversity within the products i.e. a range of hormonal methods and non-hormonal or alternatively, not LARC methods only.<sup>84</sup> We heard users' frustration that some services were unwilling, or unable, to provide them with a full range of contraception options, especially GPs who were reported to have patchy offers of LARC and/or to be unable to offer removal.<sup>85</sup>

Linking back to our findings in the <u>Non-Discrimination section</u>, some also found service providers unwilling to provide them with their preferred LARC method for a range of 'legitimate' and other reasons e.g. restricted IUD access unless the user had children already; or inaccessible facilities preventing coil fittings for wheelchair users. Others turned (or felt pushed) to LARC methods because they did not feel supported with a short-acting or permanent option. For example, numerous participants explained that professionals would not listen to their requests for sterilisation which were perceived on occasion to be tied to the professionals' preference for effective, but non-permanent LARC options:

I just wanted to know what my options were there because I know I don't want children and to be told; 'no, you're too young to make that kind of decision' was a bit hurtful because I was thinking: 'well, I've always known this.' AIMEE, 27, Interview

I felt pressure by doctors to have the implant. I want to be sterilised and I've stated this for a long time. Doctors would rather keep me on the implant.

Anon, 28, SURVEY

However, availability is only one dimension of accessibility. Person-centred access means recognising that users can experience the same method in different ways. The following tables offer insights from our data into the different faces of LARC. One column indicates the

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<sup>&</sup>lt;sup>81</sup> See for example resources such as Brook (2020) <u>Contraception</u>, NHS (2020) <u>Which is best for me?</u>, <u>Contraception Choices website</u>

<sup>&</sup>lt;sup>82</sup>Sowemimo, A (2021) A case of attempted self-removal of progestogen only implant (POI) RCOG World Congress Poster Presentation

<sup>83</sup> ANSIRH (2020) <u>IUD Self Removal</u>; Gynepunks

<sup>84</sup> FSRH (2016) Service Standards for Sexual and Reproductive Healthcare

<sup>85</sup> This is consistent with wider findings that LARC access is especially limited through GPs. See: APPG SRH (2020) <u>Women's Lives, Women's Rights: Full Report</u>

perspectives of users who found LARC methods 'right' for them, and the other indicates where LARC is definitely not acceptable albeit for the 'same' reason.

#### **PRIVACY**

#### LARC

The discreet nature of LARC methods could be helpful to keep contraception use private:

My mum found my birth control pill a few years ago and she was very angry. She's a strict Muslim and believes sex is for married couples only [...] Having an implant is discreet. She can't find it and know I'm on birth control. it's helped me take charge of my own sexual health and not let my religion/culture/family stop me from being safe. Anon, 19, Survey

#### **NOT LARC**

The 'internal' location of LARC was too invasive for that reason, was too noticeable for the user:

- It's just not very private to have it done, you know. You've got to get up on the bed, you've got to strip down, and that's not ...."
- I know that I don't want the coil or the implant, because I've always been really freaked out by the idea of having something inside me permanently. AIMEE, 27, Interview

#### **EASE OF USE**

#### **LARC**

Whilst some prefer LARC methods because they are forgettable:

 When you're living with epilepsy or anyone really, I've got a bad memory. I mean I do have to take tablets every day. But sometimes I forget them. So that's why I think it was just one thing less to think about. CLARE, 42, Interview

#### **NOT LARC**

Others experienced persistent side-effects that made LARC very memorable:

 Living in pain like 2 weeks out of a month and that's me good now, I would say, 2 weeks. I want a hot water bottle more nights in a month than I don't. I now have mottled skin at the base of my stomach which isn't a particularly great look. ROBIN, 22, Interview

#### PREGNANCY PREVENTION

#### **LARC**

High effectiveness for preventing pregnancy could be welcome.

 I'd make sure it was something that was as effective as possible because obviously if I was to get pregnant it would be hell on earth again.
 Hannah, 19, Interview

#### **NOT LARC**

Users who were not sexually active, at risk of pregnancy or ambivalent about pregnancy outcomes, were motivated by other benefits:

 But I wouldn't say that's the main reason that I have it, I'd say it mainly works for period control and pregnancy is kind of an after effect.
 NUMBER ONE, 25, Interview

#### CONTROL

#### LARC

Some found control in a LARC option:

I feel contraception is a way to take my power back when I have sex. I think that sometimes you may be in a relationship, or you may have, not accidental sex, but like risky sex. But sometimes knowing that you have contraception, especially long-term contraception, is a way of like empowering you to be like 'actually I don't have to think of ALL of the risks' because I've protected myself and done my side. ANGELA, 23, Workshop

#### **NOT LARC**

Others found the provider-dependence disempowering:

 Because I wanted something temporary that I could like monitor how I was feeling and at that time I had also started on Fluoxetine for my depression. So I just wanted to know that if I was starting to feel really bad I could like come off it.
 DA, 20, Interview

These examples highlight the ways that accessibility in terms of possibilities to 'choose the best method of contraception for you,' requires nuance and a critical understanding that perceptions of 'the best method' is not universally shared.

# LARC Professional Perspectives

We need to try and give women as many options as we can by making LARC as accessible as we can. Alison: LARC Professional: Clinical

LARC Professionals working in abortion, contraception and sexual health services shared their own concerns about the training and funding barriers that impaired their ability to offer a comprehensive service inclusive of LARC. A staff member at an abortion provider, described the pressure of being the only team member trained to fit a coil:

It does feel a bit heavy on my shoulders that I'm the only one that can do it. So, if I'm not in the clinic, you know the girls have got to book it when I'm here, in order to make it worthwhile. Paige, LARC Professional: Clinical

The impact of this unsustainable and precarious staffing structure was obvious as waiting lists could build up when the trained staff were on leave:

Nurses are trained up to do implants. But if you had say a glut of people off sick or on maternity leave and then the provision goes down and the waiting

# lists go up and you sort of get into the 3 months, 4 months waiting you know. Rachel, LARC Professional: Clinical

Mirroring the accounts from LARC users and the wider evidence base, we also heard about the pressures that have implications for access to LARC through GP services:

We're trying to get GPs trained. It's very difficult because they have lots of other pressures on their time and on their finances as well[...]And you know that, my GP colleagues tell me that the time it takes them to fit one IUD, let's say, they could have seen probably three patients or four patients and the nurse who needs to chaperone them could also have seen a couple of patients so we're talking about 5 or 6 patients you could have been seen in the time because GPs have got like 7 minutes. It's going to take you 20 minutes to half an hour to fit an IUD. So, you know, they're under pressure to see patients. Alison, LARC Professional: Clinical

And the problems related to 'timings' of LARC services and the uneven impact on LARC users, depending on their circumstances:

Because it's a procedure and people that are trained to do it, often the situation is: 'oh you've decided to have this method, and now, we have to arrange another appointment for you to come back and actually have it fitted' and that's not very practical for people. People don't want to have to come to back to a service several different times. They've got busy lives, they've got childcare issues. You know, they've got work and so if they can come to a service, discuss their needs, decide on a method, and then get that fitted at the time, then that's ideal from their point of view. Donna, LARC Professional: Clinical

Consistent with the other sections of this report and wider evidence from the SRH sector, access limitations are not only experienced by LARC users. Recessibility is a problematic area for LARC users and professionals alike and the themes across the accounts collected for this project were shared: waiting lists, training, breadth of methods available, timings and so on. Thus, where limited resources have implications for the rights of LARC users, they also infringe upon the professional possibilities of LARC providers. The wellbeing of LARC providers also appears to be compromised as they carry the burden of 'making do' with the demands of service users.

<sup>&</sup>lt;sup>86</sup> Advisory Group on Contraception (AGC) (2018) At tipping point: An audit of cuts to contraceptive services and their consequences for women; APPG SRH (2020) <u>Women's Lives, Women's Rights: Full Report</u>

# Protecting, promoting, respecting users' rights in contraceptive services

This report presents evidence to suggest that the UK is failing to protect, promote and respect the rights of all people in terms of LARC provision.

Contraception users face unacceptable time, travel and information barriers to access the care they require. The failure to provide the funding and training necessary for full, functioning contraceptive services falls short of the WHO's core availability and accessibility standards and undermines the UK's commitment to the right to health.<sup>87</sup>

LARC provision practices also fail to consistently protect informed decision-making. Everyone has the right to make their own decisions about their body. Any kind of medical treatment, including the use of LARC, requires a patient's informed consent.<sup>88</sup> If a user has not given fully informed consent, or has withdrawn their consent, the treatment will be unlawful. There is a clear lack of informed consent where services:

- do not provide a user with the information they require, in a way that they understand, on their options for contraception, the benefits of those options, and any material risks;
- pressure users (intentionally or otherwise) to choose a particular method;
- pressure users (intentionally or otherwise) to continue to use a method; or
- refuse to remove a contraceptive implant, IUD or IUS device.

Practitioners may recommend a particular contraception option. The line between a good faith discussion of the risks and benefits for a particular patient, and the kind of pressure that invalidates consent, can be difficult to judge. But service users' repeated accounts of feeling "bullied", "forced", "urged", and "pushed heavily" to choose a particular contraception method should underline the importance of centring choice in care. As expressed by Baroness Cumberlege in the 'First Do No Harm' report, informed consent will always require "a true equality of partnership in the decision-making process between patients and their treating physicians." <sup>89</sup>

A meaningful commitment to informed decision-making requires policy makers and providers to reflect on the conditions that foster pressure over users' contraception decisions. We have heard LARC professional participants share their own concerns about the impact of a 'LARC is best' culture, and particular structures like service-level LARC targets, on their ability to support service users to choose from a full range of contraception options. Providers and policy makers must remember that the best contraception option is the contraception

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<sup>87</sup> International Covenant on Economic, Social and Cultural Rights, Article 12; Convention on the Elimination of All Forms of Discrimination Against Women, Articles 12 and 16(1)(e). See also United Nations Economic and Social Council Committee on Economic, Social and Cultural Rights, General Comment No. 22 (2016) on the right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights)

<sup>88</sup> Montgomery v Lanarkshire Health Board [2015] UKSC 11; European Convention on Human Rights, Article 8

<sup>&</sup>lt;sup>89</sup> First Do No Harm: The Report of the Independent Medicines and Medical Devices Safety Review (8 July 2020) [2.17]

option that a user chooses for themselves, and must offer conditions within which this can happen.

This principle extends to the role of contraception in other support services, including the support provided for people who have experienced the removal of their children into care. While services may properly decide to provide information and promote access to contraceptive services, it is inconsistent with a commitment to users' right to informed decision-making to require one particular choice (a LARC method) in exchange for access to a much-needed, increasingly-scarce support service.

Services must work to eliminate discrimination in the provision of contraception. Those experiencing racial stereotyping, younger users and disabled users experience further barriers from services that dismiss their concerns and otherwise fail to accommodate their needs. Services must take particular care to consider the needs of those experiencing multiple forms of discrimination who are routinely marginalised.

Crucially, policy-makers and providers must work to break down the stereotypes and assumptions about who is responsible to use user-dependent contraception, and who is fit to parent, that can undermine marginalised groups' access and choice in contraception services. There must be greater education on how provider bias can influence contraceptive consultation encounters and challenges to health care prejudice.

Providers must be mindful of imposing their world view on their patients -more work must be done for providers to understand that there is significant cultural and class variation in when the appropriate time to have a child is. There should be greater emphasis on ensuring better pre-contraceptive counselling and supporting those that choose to have a child at different phases of their lives.

As outlined at the beginning of this report, there is a long, dark history of the use of contraception to prevent pregnancies that are considered social problems. In this new era of LARC policy, we must be careful to maintain respect for individuals' rights to decide the number and spacing of their children.<sup>90</sup> It requires a policy shift away from prioritising the most-effective LARC methods to definitively prevent pregnancies considered unwise, and towards a fresh consideration of how best to support individuals and their chosen families.

<sup>&</sup>lt;sup>90</sup> Council of Europe, Women's sexual and reproductive health and rights in Europe (Issue Paper, 2017) 54; and Convention on the Elimination of All Forms of Discrimination Against Women, Article 16(1)(e)

# Methodology

We conducted the research for this report between August 2019 and May 2020 in England, Northern Ireland, Scotland and Wales.

## Consultation

Between August and October 2019, we approached a range of stakeholders, both individuals and organisations, that support LARC users in the UK to talk about our plans for the project. These conversations helped us to develop our research questions and recruitment methods.

## Research ethics

The Lancaster University Faculty of Health and Medicine Research Ethics Committee (FHMREC) granted approval for the research in December 2019.

# Decolonising Contraception safe-space workshop

In February 2020 Decolonising Contraception led a workshop, 'Let's Talk Long-acting Reversible Contraception (LARC)'. Participants were recruited using an online form shared on social media platforms including Twitter and Instagram. Decolonising Contraception is dedicated to providing unique events to improve the sexual and reproductive well-being of Black and People of Colour in safe, friendly spaces. Decolonising Contraception offered a free ticket to their sexual health and well-being festival, Sexfest, as a thank you. Participants were provided with lunch and a travel reimbursement.

7 people took part in the workshop. The demographic characteristics that were collected from this group are provided in Table 1.

Table 1

|             | Workshop participant characteristics  |
|-------------|---|
| Country     | England = 7   |
| Age (years) | >25 years=5; 26-35 years =1; 35+ years = 1; (mean = 26 years)   |
| Ethnicity   | Afro Caribbean=1; Black African=2; Black (African)=1; Black/British=1; British Caribbean=1; Caribbean=1 |

#### One-to-one interviews

Between January and June 2019, we interviewed 22 'LARC users' about their experiences of LARC in the UK. We recruited people with personal experience of LARC through support organisations. Consistent with the objectives of this project, the LARC user participants for the interviews were purposively recruited i.e. selected through organisations that support people from marginalised groups, and hence are understood as likely to be

disproportionately impacted by 'targeting' with LARC methods. The characteristics of the LARC user participants is included here in Table 2.

Table 2

| Table 2               |   |
|-----------------------|---|
|                       | LARC user participant characteristics   |
| Country               | Wales= 5; Scotland =2; Northern Ireland = 1; England = 14   |
| Age (years)           | >25 years=6;  |
|                       | 26-35 years =11;  |
|                       | 35+ years = 2;  |
|                       | Not stated=3  |
| Gender                | Female = 16; Non-binary = 1; Not stated= 4; Unsure female = 1   |
| Ethnicity             | Black African=2; Black/British=1; Black Caribbean=1; Gypsy or Irish Traveller = 2; Pakistani =1; White and Asian= 1; White Irish=1; White English/Welsh/Scottish/Northern Irish/British= 9; White Traveller =1; Not stated = 3. |
| Sexual<br>Orientation | Bisexual=5; Queer=1; Heterosexual=6; Pansexual=1; Prefer not to say=2; Not stated=6, Unsure=1   |
| Education             | GCSE=2; A=levels=4; First degree=8; HE Diploma=1; Higher degree=1; No qualification=1; Not stated=4; Other (being a mother) =1  |
| Financial<br>status   | Disability/incapacity benefits = 3;   |
|                       | Carer's allowance=2;  |
|                       | None=5;   |
|                       | Not stated=6;   |
|                       | Tax credits=1;  |
|                       | Universal Credit AND Housing/heating benefit AND Carer's/attendance allowance=3;  |
|                       | Universal credit=2;   |
| Disability            | Longstanding health condition=4; Mental health condition=2; Mental health condition and other=2; No=8; Not stated=4; Prefer not to say=1  |

These interviews asked questions: to explore their experience of contraception (LARC especially)- promotion, use and removal; their experience of support; and their experiences and perspectives on 'family life' e.g. what constitutes a 'good parent.'

We also interviewed 18 'LARC professionals' who were recruited directly via email after identifying potential interviewees through publicly-available information that indicated a professional interest or expertise around LARC. We provided information on the project at a workshop in Manchester in January 2020 entitled: 'Long-acting Reversible Contraception:

Exploring Ethical Practice and Reproductive Rights in Britain<sup>'91</sup> and invited anyone who met the professional recruitment criteria to contact the research team. The professional characteristics of the LARC user participants is included here in Table 3.

Table 3

|                | LARC professional participant characteristics |
|----------------|---|
| Country        | Scotland =4; England = 14                     |
| Sector         | Healthcare=8                                  |
| (Primary role) | Social care/support=6                         |
|                | Academic=3                                    |
|                | Activist-1                                    |

All interviews LARC User and LARC Professional were conducted one-to-one in English with interviewees able to choose to speak in person or over a phone or video call. During social distancing restrictions between late March and May 2020, interviews were conducted over phone and video calls only. The researcher provided information about why BPAS was carrying out the research, how it would use the information, that they did not need to answer any questions, that they could stop the interview any time and that they could ask the researchers not to include their contribution up to two weeks after the interview. Oral and/or written informed consent was obtained from all interviewees who were given the option to use their name or a pseudonym, and choose their own pseudonym if they preferred. Professional interviewees did not receive compensation. LARC users were offered a £10 voucher to say thank you for their time.

# Online survey

The survey was designed later into the project as a response to the lockdown that arose due to the onset of Covid-19. Between April and May 2020, the online survey was distributed via BPAS social media and networks and asked people to anonymously share their experiences of LARC in the UK. The first 500 participants had the option to enter a draw to win a £20 voucher. BPAS asked a range of support organisations to share the survey with their networks through email newsletters and online groups and also promoted the survey on Facebook and Instagram.

We received 983 responses to the survey that included at least one full completed answer from three key questions, phrased as follows:

• Have you ever wanted to use a LARC method before (the implant, the coils or the injection) but found it difficult to arrange to have one? For example, trouble finding an appointment or travelling to a clinic;

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<sup>&</sup>lt;sup>91</sup> See 'Long-acting Reversible Contraception: Exploring Ethical Practice and Reproductive Rights in Britain' event website.

- Have you ever felt any pressure to use any of the LARC methods (the implant, the
  coils or the injection)? For example, feeling like there is a right thing to choose or
  feeling like someone would be unhappy if you do not choose that option;
- Have you ever wanted to stop using a LARC method (for example have your implant or coil removed or not get your next injection) and found it difficult to do so?

All of these questions had multiple-choice Likert scale response options (e.g. very difficult to not at all difficult). There was a follow up question for each which asked the respondent to explain their answer in further detail. There was also a final opportunity to share 'anything else' about the experience of using LARC.

The demographic characteristics of the 983 survey respondents are included in Table 4.

Table 4

|             | Survey respondent characteristics   |
|-------------|---|
| Country     | Wales= 32; Scotland =104; Northern Ireland = 32; England = 682; No answer = 133                             |
| Age (years) | >25 years=325;  |
|             | 26-35 years =388;   |
|             | 36-45= 134  |
|             | 45+ years = 7;  |
|             | No answer=129   |
| Gender      | Female = 839; Gender fluid=2; Male = 4; Non-binary = 6; No answer = 132                                     |
| Ethnicity   | See explanation below   |
| Education   | School level=27; Further education = 250; Higher education = 406; Postgraduate level = 161; No answer = 139 |
| Disability  | No = 649; Yes = 193; No answer =141   |

Ethnicity was enquired about using an open text question. 591 people identified themselves in some way using the terms 'White' and 'British' (60%), and 132 respondents did not answer this question at all. Of the remainder (n=260), there was a wide range of diverse self-identifications that would be problematic to consolidate into any one group and involved 'too few' respondents to classify as separate groups. As such we present here a complete list of the ways that respondents identified in Appendix 1.

#### **Analysis**

A qualitative thematic analysis was undertaken across all of the qualitative findings from the workshop, interviews and survey respectively. The data set was analysed thematically using a coding framework developed by three members of the research team (Taylor Burgess, Dr Rachael Eastham and Dr Mark Limmer), cognisant of the WHO (2014) standards for human

rights in contraception services.<sup>92</sup> These themes were compared by the lead researcher (Taylor Burgess) against the WHO (2014) standards for human rights in contraception services and the report was framed against those tenets that were found to be lacking in UK LARC provision, according to the data collected.

## Final comments and limitations

To reiterate the emphasis at the beginning of this report, it is important to remember that this is a human rights project where the methodology was devised specifically to address the 'problem' areas, i.e. where things have gone wrong or care has fallen short of the agreed standards. This critical approach is not intended to undermine the value and possibilities of LARC for many users – the many known advantages of LARC were simply not the focus of this piece of work and the resulting report. Uniquely, the emphasis is also on the perspectives and experience of LARC users concerning the framework or system of LARC provision, a perspective often overlooked in terms of evidence about contraception. The authors consider it imperative to understand LARC users' feelings and perspectives about the system as ultimately it is these feelings and perspectives which shape their decision-making and engagement (or lack thereof) with contraception and providers, e.g. poor experiences compromise trust in the system and can 'put people off' LARC methods.

As with any research, there is also transparency required and limitations that are important to address explicitly for the purposes of methodological rigour.

First the recruitment for user one-to-one interview and the workshop took place through organisations that support people who are marginalised- groups we understand are typically 'targeted' in terms of contraception and LARC use and therefore may share similar experience. However, by contrast the online survey that was open to all and shared widely on social media, offered a different demographic (see Table 4) who were also mostly *current* or previous LARC users. The survey sample, as predominantly current LARC users, could suggest this group were generally favourable towards LARC. Despite this, the survey respondents also experienced significant challenges in terms of feeling pressure towards LARC and inaccessibility of LARC methods. Ultimately, the authors are working towards the principle that 'best' provision would not involve any reported experience of pressure, discrimination or inaccessibility for any users, at any time.

Time is also salient here as although we were asking about the experience of LARC provision, there was no parameters defined for the participant's experience i.e. they could be reflecting on something that happened some time ago in circumstances that were different to now. For example, findings about the experience of pressure in postpartum care which contrast with wider current evidence on this topic that people are struggling to access any contraceptive care at all in this setting.

Despite our purposive sample strategy there were LARC users from specific marginalised groups that we were not able to recruit for this research - including substance users and individuals who had experience of their children being removed from their care. Although we did consider their experience where possible 'by proxy' i.e. through perspectives from professionals and advocates who work with those user groups. Similarly, the ethical approval

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<sup>&</sup>lt;sup>92</sup> World Health Organization (2014) <u>Framework for ensuring human rights in the provision of contraceptive information and services</u>

for our project did not permit us to recruit NHS staff. This is a limitation that would be helpful to address in the future although many of the LARC professionals interviewed have some/previous experience of NHS provision due to the NHS centred nature of sexual and reproductive health in the UK healthcare system. In addition, we reiterate here the importance of the LARC user perspective on the LARC provision system and the relevance for contraception/provider engagement.

Future work would benefit from gaining insights into a wider range of user and professional experiences. An intersectional methodology that includes analysis of structural factors would be valuable to attend to the complexity of processes that shape users experience of social inequality and associated discrimination. There were also topics or themes which warrant further exploration that were not addressed through the data collected in this research for example: access barriers related to language; and the lived experience of being a non-heterosexual or gender diverse LARC user – despite there being considerable diversity in terms of the sexual and gender identities of our interview and workshop participants, relatively little data collected addressed these aspects of identity explicitly. Similarly, there was much data collected that has not been drawn on for the purposes of this report as it was not specific to the aim of a human rights-based analysis. This presents opportunity for further exploration in future.

# Acknowledgements

Thank you to all our LARC user and LARC Professional participants. We appreciate you making the time to share your experiences.

We would like to thank all the organisations and experts that helped us to build our project plan and reach potential interviewees, especially those who work with vulnerable and minoritised demographics.

We would also like to thank our transcribing team.

# **Appendix 1**

African Asian

Black British

Black Caribbean and White Irish

Black White mixed

British

British Bangladeshi British Irish German

British mixed
British Pakistani
British/Turkish
Caucasian
Chinese British
Cornish

Dual heritage - White British, Black Caribbean

European Indian Indian British

Irish

Irish Australian

Mixed

Mixed - English/Mauritian

Mixed Asian

Mixed Asian (Pakistani) and White – British Mixed Black African and White British

Mixed British Mixed Other Mixed race

Mixed race White and Black Caribbean

Mixed Scottish and Chinese Mixed- White and Black Caribbean Mixed White and Spanish

Mixed White Asian

Mixed White English / Black African

Other White background Pakistani; Polish White Portuguese Chinese

Scottish Scottish White Traveller Welsh White

White (Other)
White American
White British Irish
White British Manx

White EU
White European
White German
White Greek
White Irish

White Irish, Iranian White mixed

White New Zealander White Northern Irish White other (dual national) White other (Turkish) White Scandinavian White Scottish White South African

White UK White Welsh

