Written evidence from SHRINE (Sexual and Reproductive Health Rights, Inclusion and Empowerment)

Executive Summary:

- The redesign of sexual and reproductive health (SRH) care brought about by funding cuts has had undesirable effects on England’s most vulnerable people, in particular those who use drugs/alcohol problematically, have a serious mental illness (SMI) and/or intellectual disability (ID).

- Due to the restructured funding, it is not affordable for services under a block contract nor those remunerated under a tariff to address the complex needs of patients who need longer and more frequent consultations or require more assertive approaches to engage in care.

- Our current service structure creates a two-tier system making it difficult for marginalised people to realise their right to health by creating access barriers that reinforce health inequalities.

- This submission explains how SHRINE is meeting vulnerable patients’ right to information, resources, services and support to improve their SRH health outcomes and how our programme is highly cost effective at a population level.

- We strongly believe it is vital for this inquiry to hear and consider the unmet needs of highly stigmatised people who are not using mainstream SRH services.

- We welcome the members of the HSC Committee to contribute to, and to share further evidence, on the research SHRINE is conducting on how best to improve the access, acceptability, availability and quality of SRH provision for marginalised populations.
1. Introduction
This is a written submission to the Health and Social Care Committee’s inquiry on sexual health from the programme SHRINE (Sexual and Reproductive Health Rights, Inclusion and Empowerment). SHRINE provides specialist sexual and reproductive health (SRH) care to people who:

- use drugs/alcohol problematically,
- have a serious mental illness (SMI) and/or,
- an intellectual disability (ID).

We are a team of SRH, addictions, psychiatric, intellectual disability and human-rights experts working together to enable people from the above targeted groups to realise their SRH human rights by improving the availability, access, acceptability and quality of SRH care. The members of SHRINE submitting this response are:

- Dr Rudiger Pittrof, Consultant in Community Sexual Health and HIV (Guy's and St Thomas NHS FT [GSTT])
- Dr Usha Kumar, Consultant in Sexual and Reproductive Health (Kings College Hospital NHS FT [KCH])
- Elana Covshoff, SHRINE Programme Manager and Human Rights Specialist
- Dr Shubulade Smith, Consultant in Psychiatry (South London and Maudsley NHS FT [SLaM])
- Rosie Mundt-Leach, Head of Nursing, Addictions Clinical Academic Group (SLaM)
- Alan Schofield, Rights Holder and Patient Expert
- Sue Mann, Head of Evaluation, Medical Expert and Public Health Consultant in Reproductive Health
- Katia Narzisi, SHRINE Research Assistant
- Alanna Jamner, SHRINE Project Support

2. Why are people with addictions, SMI and/or ID important to your inquiry?
SRH services across England have adapted to funding cuts by redesigning their care pathways. Service provision is more efficient now as the departmental restructures have made cost savings. Services are concentrating more on their core business which is preventing and managing STIs and unintended pregnancies.

This, however, also has unwelcome consequences. For services under a block contract that have to see a certain number of patients, it pays to see as many uncomplicated patients as possible. For patients remunerated under a tariff it pays to see patients who have a condition(s) that are rewarded by the tariff. It is not desirable for either service to seek out complex patients who need longer and more frequent consultations. These patients often come from marginalised and overlooked population groups, resulting in high levels of unmet SRH needs among vulnerable groups. To address this issue, SHRINE is a specialist service that uses a human-rights based approach in looking after the SRH needs of people with addiction, serious mental illness (SMI) and or intellectual disability (ID). We are unique in the UK, perhaps in the world, and would like to give evidence on behalf our often invisible client group who do not access traditional, mainstream SRH services (Edelman et al 2014, Edelman et al 2013, Parlier et al 2014).

Mental health (MH) and addiction problems are common.

- Mental ill health is the single largest cause of disability in the UK, contributing up to 22.8% of the total burden, compared to 15.9% for cancer and 16.2% for cardiovascular disease (Department of Health).
- 4.3% of men and 1.9% of women in UK are drug dependent (Adult Psychiatric Morbidity Survey, 2014).
- The lifetime prevalence of psychotic disorders is about 3% (Perälä et al 2007, Kirkbride et al 2012);
- In 2012 the estimated prevalence of mixed anxiety and depressive disorder amongst adults in England was 9.2% (Public Health England).

It makes sense for SRH service providers to de-prioritise the SRH needs of these populations because to reach them requires a more expensive outreach and partnership working approach. Leaving their needs unmet exacerbates health inequalities and is a false economy at a population level.

3. Evidence
The following examples are drawn from real scenarios from SHRINE’s frontline clinical work. Each example shows how SRH issues can affect people with SMI/addictions and have a large impact on the patient's health and wellbeing. They also show how SRH issues for people with SMI/addictions can have high costs to health and social care. All names have been changed to protect patient confidentiality.

I. **Brendan (28 years old) lives in a hostel, has schizophrenia and is taking risperidone. He stopped taking his MH treatment because he met someone he wants to start a relationship with and he finds his medication interferes with his sex drive and function. The hostel staff found his behaviour too difficult one night and were concerned for both Brendan’s and the staff safety. The hostel staff called the police. SHRINE saw Brendan while he was an inpatient on an assessment ward at the Maudsley Hospital while being detained under Section 2 of the Mental Health Act.**

MH conditions affect a person’s SRH needs in various ways: people with depression may lose interest in sex or people with manic symptoms may participate in increased risky sexual behaviour (Marengo et al 2015). Sexual dysfunction is a common reason for defaulting on antipsychotic and antidepressant treatment. This issue is under-recognised by MH professionals. Sexual dysfunction affects between 38-86% of patients (Montejo et al 2018) and sexual side effects are a common reason for discontinuation.
of antipsychotic medication (Dibonaventura et al 2012). Poor adherence to antipsychotic medication substantially increases the risk of a psychotic relapse and readmissions increasing the risk of long-term psychiatric admission. The average cost of an inpatient bed in England is £350 a day (Department of Health, 2013), while the median length of stay for schizophrenia is 38 days, giving a total cost per typical admission of £13,300 (Knapp et al 2014).

II. Mary (36 years old) has recently been discharged from prison for drugs related offences. She attends drug treatment sessions regularly as a condition set by her probation officer. A SHRINE doctor arranges to attend one of her probation meetings to discuss her SRH needs, in particular contraception. She has had 2 children removed into care in the past and does not want to get pregnant now because she is trying hard to get her life back on track after prison.

For women with addiction problems and/or SMI, pregnancies are frequently complicated. When pregnancies do occur they are often recognised late, and involve minimal or erratic access to antenatal care. It is common for these pregnancies to have medical complications with maternal and neonatal biomedical or psychiatric morbidity, often resulting in an increased risk of antenatal and postnatal hospitalisation. The woman will often experience distress if the baby is taken into care at the time of or soon after the birth which may trigger a relapse in her mental health or addiction. While this outcome is well known by health and social professionals, two recent systematic reviews found no effective interventions to promote sexual health (Pandor et al 2015) or prevent HIV (Wright et al 2014). We could find no recent publication addressing contraception provision either.

III. Client ‘S’ is 21 years old. She has been known to the care system from the age of 11, a victim of domestic violence, mental health issues, cannabis daily, poor diet and low mood. She had three previous pregnancies and previous children were removed into care. The judge agreed for “S” to be placed into a psychiatric parenting assessment unit. A contraceptive implant was inserted on day 2 on the postnatal ward. Mother and baby are now home and co-parenting with the father. “S” said ‘having an implant has given me the chance to get my life in order and make things go right for my baby and myself. I never thought that I could do this but now I feel I can.’

Another woman who had her first 2 children removed into care and received a postpartum implant from her midwife and with support from social care was able to look after her 3rd child said: “not falling pregnant again quickly gave me the opportunity to look after my baby and myself... I am so happy.”

The removal of a child from the mother and placed into care is a common outcome for babies of women with SMI, ID or addiction. Without proper access to and use of contraception, these women can expect to be pregnant soon or shortly after their most recent pregnancy. The accepted standard of care should include the provision of contraception shortly following delivery on the postnatal ward. However, this hardly ever happens as immediate postpartum contraception is not commissioned by local authorities, CCGs or NHS England. In Southwark, 32% of applications to take children into care were for children with mothers who had already had a child previously removed into care (Broadhurst, 2015). The cost of one child going into care from the time of birth to their 18th birthday costs about £650,000 to social care. Poor access to contraceptive counselling and services for women with addiction or psychotic illness is likely to lead to even more children going into care. Furthermore, the emotional cost to the
mother often results in the situation repeating itself until help is offered. SHRINE developed and piloted a very successful contraception training course for the midwives at St Thomas Hospital that trained them to provide Progestogen only methods of contraception during the 6-week postnatal following delivery. This training won the Burdett Trust’s Maternal Health Award 2018.

IV. A female, street-based sex worker in Lambeth with a £200/day heroin and crack dependency can ask for £10-20 per transaction (less if she insists on using condoms) (BBC, 2016). She needs about 30 clients a day to feed her addiction – every day of the week. If she catches syphilis it will cause an epidemic (80% transmission rate per sex, duration of infectivity 1-2 years, 10 clients per day, cost per case treated in a specialist service £240). Nearly 3,000 new cases per year will cost about £700,000 to treat.

4. Recommendations
The right to SRH is an essential part of the right to health but the realisation of SRH and human rights often remains beyond the reach of people with addictions, mental illness or intellectual disabilities. They continue to be vulnerable to experiencing violations of their rights and autonomy. Health is not only about the absence of disease and SRH is central to people’s overall health and wellbeing. We should be aiming to meet the integrated definition of SRH and rights outlined in the recent Guttmacher-Lancet Commission (2018).

Our current recommendations are:

I. Amend the Pan-London Tariff: The current London Integrated SRH Tariff does not reward the quality care that is needed to engage at-risk and hard to reach patients who do not attend mainstream SRH clinics. It needs to fund service providers appropriately for the time and resources used to see complex patients.

II. Fund Assertive Outreach: SHRINE’s research shows targeted community outreach is an effective prevention intervention for marginalised populations who are a high cost to both health and social care. Targeted community outreach should be included in service specifications by commissioning.

III. Include SRH Outcomes in Service Specifications across Health and Social Care – SRH intersects with every facet of someone’s care. SRH service providers need to be working in greater partnership with their colleagues in social care, mental health, criminal justice, housing and etc. For example, we are missing the opportunity to maximise the potential of the recent sizeable investment in mental health services. SRH and mental health continue to work in silo and signposting between the two is confusing and difficult for a patient to navigate. Commissioning can incentivise service providers to work together by stipulating SRH indicator outcomes in mental health service specifications. This would build referral pathways between services, improve communication and embed specialist SRH input into the care planning for mental health patients.

5. Conclusion

SHRINE believes that the current SRH services try their best but often fail to meet the needs of the most socially deprived and vulnerable in society as the current services are designed with non-marginalised
people in mind. For example, internet booking of appointment works very well for literate people with access to smart phones or computers who can plan their day independently.

Where SRH care is provided for marginalised people there are often wider benefits beyond the intended outcomes, which are not being realised by commissioning bodies who only look at simple, easy to count outcomes. An example for this is given by Georgina Perry, the former manager at Open Doors who resigned when the service’s funding was cut by 43%. In an interview with the Guardian she explained, “At one point we had 12 individuals out of 120 living with TB-HIV co-infection. These are really terrible statistics. When we first started with our street sex workers virtually 100% of them were homeless, they didn’t have GPs, [and] they were using A&E as their primary care. I feel really sad that we are going to go back a decade or more, because we will (McVeigh&Eastham, 2016).”

SHRINE is providing assertive outreach and is using an inter-professional approach in all of our work. Our research will provide evidence to better understand the needs and barriers to accessing care for our patient groups. We are also evaluating and will be producing research on the impact of working this way to develop a set of principles to underpin best practice in service delivery for marginalised populations.

We welcome the opportunity to present our findings to the HSC and for the committee’s members to participate in our on-going research until 2020 to improve the access, acceptability, availability and quality of SRH for marginalised populations.

Kindest Regards,

The SHRINE team

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