MINUTES OF THE MEETING HELD 26TH JANUARY 2022

12:00 – 13:00, ZOOM

PRESENT: Jenny Rathbone MS (Chair), Sioned Williams MS, Delyth Jewell MS, Kirsty Rees (office of Mike Hedges MS), Chloe Rees (office of Sarah Murphy MS), Heledd Roberts (office of Rhun Ap Iorwerth MS)

IN ATTENDANCE: Katharine Gale - Royal College of Nursing Wales, Angharad Jones- RCOG Council Members' Representative for Wales, Jane Dickson - ABUHB Clinical Director, Amanda Davies - SBUHB Consultant SRH, Louise Massey - ABUHB Consultant in Sexual and Reproductive Health, Helen Munro – HDUHB Consultant, Lisa Humphrey - HDUHB General Manager, Caroline Scherf - Cardiff & Vale UHB consultant SRH, Helen Bayliss - Cwm Taf NHS Trust, Rachel Gilmore - Cwm Taf UHB, Judy Thomas - Community Pharmacy Wales, Bethan Edwards - Marie Curie, Deborah Shaffer - Fair Treatment for the Women of Wales, Viv Rose - BPAS Cardiff, Katie Walbeoff - Public Health Wales (Cervical Screening), Lisa Nicholls – FTWW, Rhianydd Williams – TUC Equality and Policy Officer, Pauline Brelsford - Abortion Rights Cardiff, Lucy Cohen - Patient Campaigner, Alison Scouller - Socialist Health Association Cymru, Bronwen Davies - Abortion Rights Cardiff, Jude Rosenberg – expert patient, Diana Dobrzynska – BPAS, Richard Harrison - Uni of Reading Postgraduate Research Assistant, Lara Morris – FTWW, Aimee Ehrenzeller - Ashgrove Surgery Physician Associate

1. MINUTES OF THE MEETING HELD 8TH JULY 2021 AND MATTERS ARISING

Clarification of minutes dated 13.10.21: Helen Munro flagged that minutes should be amended to indicate that pathways into specialist menopause service can and should happen via gynaecology or SRH, not solely SRH, but there must be equity between services. With this change, the minutes from the previous meeting were agreed.

Matters Arising: Eluned Morgan MS responded to the CPG letter regarding menopause care and advised that the Women's Health Implementation Group will discuss the menopause issues raised by the CPG.

2. PAIN DURING GYNECOLGICAL OUTPATIENT SETTINGS

Lucy Cohen – Patient Campaigner

- Lucy had an IUD fitted May 2021. She anticipated the procedure may be uncomfortable but was advised by GP that paracetamol would suffice. Lucy described the procedure as the most painful experience of her life and it left her in shock.
- Lucy shared her experiences on social media and others started sharing similar experiences with her. This prompted Lucy to begin collecting the experiences of other women via a survey. A large percentage of respondents rated their pain as 9/10 out of 10 – not the mild discomfort described by the NHS website..

- Lucy's campaign is calling for minor gynae procedures to be treated with the gravitas of other procedures.

Louise Massey – Consultant in Sexual and Reproductive Health

- Louise is an experienced coil fitter who specialises in complex cases. Louise advocates for widespread use of local anaesthetic for straight forward coil fittings. From her experience there are three things that make a difference to women's comfort during coil fittings: empathetic clinic and assistant, lidocaine spray to the cervix, injectable anaesthetic.
- Much like going to the dentist, where painkillers are injected in the area of the mouth where a procedure will take place, the same principle should be applied to coil fittings.
- Lucy and Louise have been working together to create a pathway that patients could use for themselves to decide their risk factors for having a painful procedure. Not every provider can have all kinds of pain relief but if patients are able to identify and decide what level of pain relief they might need, they can choose a provider accordingly.
- There is resistance to introduce widespread use of injectable pain relief due to concerns that providers will be overwhelmed and unprepared.
- Competency frameworks from bodies like the FRSH should be strengthened to make sure practitioners are assessed in choosing and delivering appropriate pain relief.

Rich Harrison – Reading university

- Rich is researching experiences of pain during hysteroscopy (a procedure where a camera is put through the cervix to examine the inside of the uterus)
- Analysed data showed a worryingly large proportion of patients reported intense or frequent pain and that there was a disconnect between the patient and clinician estimates of pain.
- Most reports indicate no anaesthetic was given at all and the maximum dose was delivered very rarely.
- Comparisons between hysteroscopy pain to period pain made in other studies, make problematic assumptions about the levels of pain experienced during periods and could potentially lead clinicians to advise patients on unrealistically low expectations of pain levels.
- The team at Reading University hope to start developing predictive pain assessment to help pinpoint the patients that need more anaesthetic and support.

3. DISCUSSION OF ISSUES RAISED BY SPEAKERS

Discussion focused on experiences from other patients, the administration of pain relief for procedures, issues associated with perception of women's pain more broadly and the need for better research and guidance.

Further Patient experiences:

- Another patient campaigner shared their experience of getting IUD fitted and of a hysteroscopy described the pain as excruciating in both instances and felt unsure of whether she was allowed to ask for pain relief and felt she had to put up with the pain.

- A different patient described her experience of a biopsy: *"I thought I knew what pain was. The procedure was caveated in assurances that most women don't feel anything, a tight pinch perhaps, something like period pain. I was told to breathe through it, as I was showing distress. I haven't got words for the pain, I'd hate to overplay it but it honestly felt torture and I felt under pressure to say I wasn't in pain*."
- Patients expressed their frustration at the language used around gynaecological procedures and felt the downplaying of pain was unfair to women.

Perceptions and communication of pain:

- It was suggested that the issues raised by campaigners and patients speak to a wider issue of perceptions of female pain and women not being listened to. Some women speak about being 'medically gaslit.'
- Setting low expectations of pain whilst knowing how painful procedures can be risks defiance of medical ethics and may well make pain worse by breeching expectations. This mismanagement of pain expectation also risks discouraging women from returning for other procedures.
- During a procedure it can be difficult for patients to communicate pain for many reasons, if pain reaches trauma levels it's hard to communicate; people who are neurodivergent or have previous experience of sexual trauma may find it hard to communicate pain
- Pain changes a lot from one person from one person to the next, from a clinical perspective it's hard to accurately estimate how painful someone may find a procedure

Training and Research:

- Helen Munro: The FRSH are keen to support the work that Louise and Lucy are doing and recognise that current training may be inadequate when it comes to pain relief element of coil insertions
- Katherine Gale (RCN rep): During training for nurses there is a huge emphasis on choosing who is suitable for outpatient procedures; predictive factors for pain should be discussed so women are able to make an informed choice about whether they're happy to go ahead with an outpatient procedure for hysteroscopy
- Hysteroscopy training for nurses makes clear that patients should be told that at any point the procedure can be stopped. Is there a difference between the training doctors and nurses get?
- There is not enough good quality evidence to suggest that using lidocane block on every patient would improve overall pain relief; there needs to be more research to support that.
- Those conducting current research and pilots relating to pain during gynaecological outpatient procedures agreed to connect outside the meeting to discuss how they might be able to work together.

4. AOB

- Update on telemedical abortion care: There is political nervousness on telemedical abortion care; providers and campaigners are continuing to push for evidence-based care. We expect a decision soon.

- Update on abortion services in Wales requested for next meeting

5. FUTURE MEETINGS:

Next meeting: May 2022, Zoom, **Topic:** Women's Health Strategy for Wales presented by FTWW and BHF