

Written evidence from Dr Abigail Niven and Dr Francine Toye, University of Oxford [WRH0013]

Evidence to the women's reproductive health inquiry

We (Dr Abigail McNiven and Dr Francine Toye) have co-led a study titled 'PURSUE', funded by NIHR Policy Research Programme on experiences of urogynaecological conditions (including pelvic organ prolapse and urinary incontinence) and related health services (ref: NIHR202450). The study involved interviewing n.74 people (primarily cis-gender women) in the UK about their experiences of symptoms, quality of life impacts, consulting healthcare professionals, navigating health services, and treatments and outcomes, amongst other topics. The study ran from March 2021 to February 2023. We produced a number of outputs which provide more detail on these various topics, including academic articles, presentations, a patient-facing online resource also for use in medical education and teaching (<https://healthtalk.org/Urogynaecological-conditions-and-pelvic-floor-problems/overview>) and a service improvement resource (<https://healthtalk.org/Urogynaecological-conditions-and-pelvic-floor-problems/Catalyst-film-for-service-improvement>), with further outputs in production.

The study was informed by several qualitative evidence syntheses undertaken by Dr Toye with colleagues (Toye, F., Pearl, J., Vincent, K. and Barker, K. (2020) A qualitative evidence synthesis using meta-ethnography to understand the experience of living with pelvic organ prolapse, *International Urogynaecology Journal*, 31(12), pp.2631-44.; Toye, F. and Barker, K. (2020) A meta-ethnography to understand the experience of living with urinary incontinence: 'is it just part and parcel of life?' *BMC Urology*, 20(1), pp.1-25.; Izzett-Kay, M., Barker, K., McNiven, A. and Toye, F. (2022) Experiences of urinary tract infection: A systematic review and meta-ethnography, *Neurourology Urodynamics*, 41(3), pp.724-39.), and in response to a commissioned call recognising a gap in qualitative evidence and in the context of the Cumberlege report and Women's Health Strategy for England.

With regards to the specific questions outlined by the inquiry:

- **What constitutes healthy periods and reproductive health?**

We heard in the interviews about experiences regarding urogynaecological health across the life course. Pregnancy, postnatal, peri/menopause and ageing were all important points and processes. A general sense of the normalisation of urogynaecological problems, and particularly with regards to these lifecourse aspects, could make individuals feel their symptoms and the detrimental impacts on their lives were unimportant, trivial and something they should learn to accept, to the extent that some felt there was little to no point in seeking help because they did not think anything was available or that it would not be offered to them (from healthcare or more broadly from their social circle and relationships). Some described feeling ill-prepared for urogynaecological bodily changes and conditions, feeling that it was not a topic of conversation in society or in medical content enough; for some, there was a sense of stigma, shame and embarrassment because of links with sex, genitals, bodily fluids and bodily boundaries. Some people felt it was solely their responsibility to accept and manage their symptoms/conditions; this included putting the onus on themselves to do (or have done) pelvic floor exercises to improve symptoms or maintain a healthy pelvic floor, though many had never had detailed instruction on how to effectively do these.

- **What are women's experiences of being diagnosed with, undergoing procedures and being treated for gynaecological or urogynaecological conditions?**

Diagnosis could be straightforward via primary care for some; however, for others, it could

involve multiple steps - including building oneself up to book an appointment or raise concerns about symptoms, examinations/tests and referrals. Having a diagnosis revised (e.g. around bladder pain and function symptoms) or otherwise expanded (for example to include multiple types of prolapse or severities of prolapse) could be upsetting, but also many found it important to have more detail and informative for considering treatment options. Experiences of decision-making and experiences about investigation and treatments varied, with some finding these relatively smooth and unproblematic whilst others felt there were issues around communication (e.g. in advance of tests) and the tests and treatments themselves could be physically uncomfortable and embarrassing. Some people reported feeling 'fobbed off' by a lack of investigation, referral and/or treatment options being offered to them; others felt that the information they gave them rushed them past conservative options and into surgical options too quickly.

Of our sample, n18 women had undergone mesh, with n.16 of these reporting mesh complications. Our published paper (Toye, F., Izett-Kay, M., Barker, K. and McNiven, A. (2023) The experience of women reporting damage from vaginal mesh: a reflexive thematic analysis, *eClinicalMedicine*, 58. Doi.org/10.1016/j.eclinm.2023.101918) outlines their experiences, including the physical and emotional impact of mesh injury, the sense of feeling treated like 'meat', damaged trust in healthcare professionals and services, and the difficulties around considering mesh removal.

- **What disparities exist in the treatment and diagnosis of gynaecological or urogynaecological conditions?**

We deliberately sought to hear a wide variety of experiences across the interviews with a maximum variation sample. Whilst our sample was limited in terms of diversity of those from ethnic minorities and lower socioeconomic backgrounds, age range and disability were two areas where the sample was strong and participants described how these aspects impacted on their experiences. Some felt there were associations between particular ages and conditions, which could be unhelpful (for example, feeling an anomaly for being a younger person with urinary incontinence, vs feeling trivialised as an older person with urinary incontinence). Having existing health conditions and other commitments (including caring responsibilities) could make it challenging to prioritise (or have prioritised) their own health needs and concerns with regards to urogynaecological symptoms and conditions. Our sample was from across the UK and we also heard about geographical disparities in terms of specialists.

- **What barriers exist in the treatment and diagnosis of gynaecological or urogynaecological conditions?**

The barriers vary for different individuals and groups, and can combine to present challenges for patients in accessing and continuing in health services for diagnosis and/or treatment (e.g. feeling urogynaecological problems are normal/normalised, embarrassment about symptoms, believing that medical help is not available or likely to be forthcoming, having too many commitments already to juggle, worries about dismissive responses or having had previous or heard about others' experiences of this, and feeling no progress was being made or made quickly enough with investigations and referrals). We heard about the impact of COVID-19 on accessing healthcare, and more broadly about long waits to access specialist services.

Communication about and support with decision-making around treatments is key; for example, communication from healthcare professionals and knowledge held by patients about conservative treatment options, including pessaries for prolapse, was not always consistent and sufficient, and the public profile of mesh injury impactful on considering other surgical options and potential outcomes. As noted earlier, we heard about delays in accessing specialists and limitations in support with decision-making about treatment options.

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