



Barriers and enablers to participating in regular screening programmes for women with cerebral palsy: A qualitative life course study.

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Barriers and enablers to participating in regular screening programmes for women with cerebral palsy: A qualitative life course study.

ABSTRACT

Aims: To determine the barriers and enablers to **regular, women-oriented screening programmes** for women with cerebral palsy (CP); and to discuss the participants' suggestions for change.

Design: Qualitative life course approach.

Methods: Twenty five life course interviews were conducted with women in 2020 who identified as having a diagnosis of CP. Interviews were conducted in person or using electronic platforms. Framework analysis was used to interpret the data.

Findings: Access and utilisation of **regular screening programmes** for women with CP across the life course is determined by multiple socioecological factors. Three themes are discussed focusing particularly on cervical and breast screening: **1. barriers, 2. enablers, and 3. women's suggestions for change.** Some women chose to opt out of sexual health checks for fear they would be too uncomfortable or the procedure would be too difficult. Practitioner attitudes towards disability in general, as well as the extent to which they understood the effects of CP for women, was highlighted as a barrier. Accessibility and adaptability of the environment also influenced women's uptake of **screening.**

Conclusion: Women with CP face many challenges to their sexual and reproductive healthcare. These can deter them from participating in **regular women-oriented screening programmes, which puts** them at higher risk of preventable diseases. Understanding the lifelong effects of CP for women, and the interaction with **their** reproductive health could help to reduce unmet needs and increase participation in **relevant screening** across the life course.

Impact: Knowledge of the challenges to **regular screening programmes** experienced by women with CP across the life course is crucial to provide appropriate preventative health care for women with CP across different stages of life. Elements of this knowledge could have benefits for the care of all disabled women.

Keywords: **women-oriented screening programmes**, reproductive health, disability, women with cerebral palsy, cervical screening, mammogram, **breast screening**, qualitative.

INTRODUCTION

Cervical **screening** tests and mammography (breast screening) are widely recognised procedures offered routinely to all women in the UK above the ages of 25 and 50 respectively, for the early detection of cancer in different stages of life (Duffy, Tabár, &

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3 Smith, 2002; Kilic, Tastan, Guvenc, & Akyuz, 2019). The primary purpose of such screening
4 methods is to identify abnormalities prior to symptoms, triggering the administration of
5 preventative treatment. Screening has great benefits, and ultimately saves lives. In the UK for
6 example, approximately 4500 women's lives are saved every year as a consequence of
7 cervical screening (Wilacy & Tiley, 2021). For breast cancer, the most prevalent form of
8 cancer for women worldwide, the survival rates have increased with advances in treatment,
9 early detection via routine screening programmes and a greater general awareness of the
10 disease (Nuffield Trust, 2021). Disease prevention is relevant to **disabled women, including**
11 **those with cerebral palsy (CP)**, as much as to women without perceived impairments.
12 However, a plethora of evidence **reports barriers to participation in women-oriented screening**
13 **programmes for disabled in comparison to non-disabled women** (Fasen et al., 2020; Horner-
14 Johnson, Dobbertin, Andresen, & Iezzoni, 2014; Kilic et al., 2019; Ramjan, Cotton, Algosu,
15 & Peters, 2016). **For example, in Kilic et al's (2019) qualitative study with women with**
16 **physical impairments, barriers to participation included structural and environmental barriers**
17 **(e.g. lack of adjustable equipment, few facilities for disabled patients) and a limited**
18 **knowledge of disability among health care professionals (HCPs). A review of literature on**
19 **barriers to women-oriented screening for disabled women (Ramjan et al, 2016) highlighted**
20 **that disabled women in general were less likely to participate in screening due to both**
21 **physical barriers and not having their needs understood by HCPs.** In addition, research has
22 demonstrated that nurses do not focus on the impact of disability on sexual health (McCabe
23 & Holmes, 2014).

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30 **Whilst these international studies have explored the screening experiences of disabled women**
31 **in general, none have focused on the needs of women with CP in particular.** This paper
32 reports on findings from (to our knowledge) the first UK ethnographic study to explore the
33 sexual and reproductive healthcare experiences of women with CP at different times in their
34 lives. In this article, we report on the *barriers* and *enablers* experienced by women with CP
35 in relation to **regular preventative screening programmes** during different points in their lives
36 (from youth to older life); and on *women's ideas for changes* in practice to reduce structural
37 barriers to such **programmes**, make reasonable accommodations to services and procedures,
38 and increase awareness among disabled women of the importance of preventative screening
39 across their lives.

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43 **Taking a qualitative life course approach to the sexual health of women with CP is useful in**
44 **order to learn about the dynamic nature of their health over time. This involves considering**
45 **how individual trajectories unfold, and the personal, social and psychological resources**
46 **women draw upon that can either enable or hamper their long-term health and wellbeing, the**
47 **extent of their vulnerability or resilience, and long-term recovery or decline (Burton-**
48 **Jeangros, Cullati, Sacker, & Blane, 2015). This paper presents evidence of the biological,**
49 **physical and social issues to influence access to and the quality of women-orientated**
50 **screening for women with CP in different stages of their lives.**

51 52 53 54 55 56 BACKGROUND

57 CP has been conceived as a non-progressive impairment caused by damage to the brain
58 before, during or soon after birth. **Clinical** guidelines (Shaunak & Kelly, 2018) estimate that 2
59 to 3.5 per 1000 live births in UK result in a child with CP. The disability charity Scope
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(2020) estimates that approximately 1,800 children are newly diagnosed with CP every year in the UK; with an estimated total of 30,000 children and 130,000 adults currently living with CP. Given the global prevalence of disability is higher for women than men (World Health Organization, 2016), it can be deduced that women with CP are a growing group, one which has the same **health care** needs and rights as all women. However, most research and service provision has focused on children with CP, or the needs of their parents: **we conducted a brief search in JAN 2011-2021, which** lists 18 studies on disabled women, **with** only one on CP: half were focused on caregiver needs (**including the CP one**). There is little if anything, it seems, systematic follow-up for adults with CP, especially focusing on the female life cycle.

In England, the National Health Service (NHS) offers two regular women-oriented screening programmes. First, cervical screening is available to all women and people with a cervix aged 25-64. Invitations are sent out to those eligible at age 24.5 and up to age 49 receive these every three years, then every five years to age 64 (Public Health England, 2021). Second, every three years all women aged between 50 and 71 who are registered with a general practitioner are automatically invited for breast cancer screening through mammography(NHS England, 2019).

There is strong evidence **though** that women with physical impairments miss out on preventive treatment, **such as these women-centred screening programmes**, due to multiple-level barriers including personal fear, lack of physical access to the service, negative attitudes from healthcare workers, lack of adaptable equipment (Kilic et al., 2019; Poulos, Balandin, Llewellyn, & Dew, 2006; Shah, Bradbury-Jones, & Taylor, 2020). In a survey of women with CP, Nandam et al. (2018) reported several barriers to breast screening, including lack of reasonable accommodations like a wheelchair or accessible mammogram machine, or no staff training on modified positioning techniques. The mechanics of the mammogram procedure requires women to stand holding onto the mammography machine to balance herself (if required) and remain motionless during exposure, which is often very difficult for women given the physical effects of CP (Poulos et al., 2006). The natural reaction may be to offer physical support, involving for example a technician handling the women's breasts to ensure they are in the correct position to be X-rayed. This is not always acceptable without appropriate consent, and could provoke frustration and embarrassment for both the patient and technician.

Limited literature exists about the experiences of **preventive screening** for disabled women across the life course, and even less **so** in relation to women with CP. A few international quantitative studies exist (from middle income countries, precluding the UK) focusing on other aspects of **sexual and reproductive health** for single generational cohorts of females with CP. For instance, studies by Zacharin, Savasi, and Grover (2010) and Flavin, Shore, Miller, and Gray (2019) focused on the interplay of CP impairment, menstruation effects and menstruation management practices, and patterns of prescriptions for teenage girls with CP. In terms of **reproductive** health of women, studies have found **that maternity health care providers have the general perception that disabled women will not pursue sexual relationships or become pregnant (Hayward et al., 2017). They tend to lack the knowledge and experience to treat disabled women who are pregnant and expect these pregnancies to be associated with complications and poor outcomes (Mitra, Long-Bellil, Iezzoni, Smeltzer, & Smith, 2016). The few studies focusing on women with CP and pregnancy found that women experience a decline in physical mobility and function after pregnancy, yet there was no evidence of specialist accommodations in place for these women, either before, during or**

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3 after childbirth (Hayward et al., 2017; Sundelin, Stephansson, Johansson, & Ludvigsson,
4 2020).
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7 The study by Nandam et al. (2018) was the first to focus on breast screening of women with
8 CP. It evidenced that there was a lack of reasonable adjustments, in healthcare facilities, to
9 accommodate women's inability to use standard equipment due to involuntary movements,
10 dexterity or mobility difficulties. The authors identified this as a barrier to breast cancer
11 screening compliance for women with CP, which they reported as lower than that for the
12 general population. They concluded that girls and women with CP experienced inequalities in
13 their receipt of sexual health treatment (Nandam et al., 2018).
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16 There is therefore very little known about the sexual and reproductive needs of women with
17 CP in different generational stages of their lives; the effects of CP impairment in adulthood;
18 and how it affects the administration and quality of women-oriented screening. What has
19 been written has largely focused on breast screening. As a result, women with CP are less
20 likely than their non-disabled contemporaries to have their needs routinely checked and met
21 adequately and in a timely way. Cancer Research (2017) reported that disabled women are a
22 third less likely to participate in breast screening, and a quarter less likely to be screened for
23 bowel diseases compared to non-disabled women. Grono (2016) reports that higher health
24 risks for disabled women are due to multiple barriers to treatment, practices and physical
25 environments.
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28 29 THE STUDY

30 31 Aim

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33 This paper reports on the service user perspectives as part of a larger qualitative study
34 undertaken between March 2019 and April 2021. The main study explored the sexual and
35 reproductive health care experiences of women with CP across the life course; and the
36 experiences of nurses and midwives in relation to providing care to this patient population.
37 The main research questions were: How do women with CP experience sexual and
38 reproductive healthcare over the life course? What helps and what makes this
39 difficult/challenging? This paper focuses only on the women's experiences of regular
40 screening programmes across the life course (cervical smears and mammograms), and the
41 barriers and enablers to their participation. It also reports on the women's suggestions for
42 change in relation to screening procedures for women with CP in particular and disabled
43 women in particular.
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48 49 Research Design

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51 We drew on Elder's life course approach, emphasising the importance of understanding the
52 interplay between the social and biological (Elder Jr, 1994), as well as addressing the
53 complex interactions between the biological and the social that influence health trajectories of
54 women with CP. For instance, influence of exposure to disability discrimination in childhood
55 and youth (i.e. low expectations of achieving normative life course milestones, and
56 assumptions of asexuality), on disabled women's long-term health behaviours and knowledge
57 about the importance of preventative health checks. Further, impact of early eugenic
58 philosophies and the historical devaluation of disabled women on the direction of life
59 trajectories and access to and utilisation of healthcare (Shah & Priestley, 2011). Life-course
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theory has been shown to be enormously helpful in providing a roadmap to inform nursing (Kitson et al., 2021; McCabe & Holmes, 2014).

A qualitative life course approach (Shah and Priestley 2011)

was therefore adopted to generate women's perspectives and experiences of women-oriented screening programmes. The interviews were designed to be both retrospective and prospective, to generate women's experiences in relation to sexual health and health care across the female life cycle, from menarche to menopause. Interviews with women were all undertaken by [initials], a woman with CP with extensive experience of qualitative interviewing. We followed the Consolidated criteria for Reporting Qualitative Research (COREQ) guidelines (Tong, Sainsbury, & Craig, 2007). The research was co-produced by people with CP and their supporters from inception through to completion.

Participants, sampling and recruitment

In order to be included in the study, participants had to be women with physical impairments resulting from CP; aged over 14 years; be geographically based with the UK; and have the capacity of participate and consent. We used both purposive and maximum variation sampling techniques to recruit participants to the study (Patton, 2002). The recruitment process started in October 2019. Digital and non-digital strategies were employed to notify, recruit and interview the target sample. A short advert about the study was emailed to UK organisations for and of disabled people in general, and people with CP in particular, to share it with their members and customer base (via e-newsletter, twitter or Facebook feed). Study information was also posted onto closed Facebook groups specifically for adults with CP and disabled women, and onto Twitter where it was retweeted by disabled people, disabled people's organisations and disabled academics. The fact that [initials] is herself a woman with CP granted her access to a number of closed social media platforms, including Facebook groups *Cerebral Palsy Adults Advice UK*; *CP Hub*; *Hardcore AAC* (a collective of people who use augmentative and alternative communication); *Sisters of Frida*, a discussion group for disabled women. Snowballing techniques were also utilised, whereby existing participants shared information about the study to their own networks.

We sought diversity in social class, age, and classification of CP. Central motor dysfunctions may be spastic, dyskinetic, mixed, ataxic and hypotonic (Fasen et al., 2020) with regional distribution of affected function such as hemiplegia, diplegia and quadriplegia (Scope 2018) (see table 1). Digital strategies facilitated consent among women with CP, their participation in research interviews, and communication with the research team, without necessarily relying on others for physical or communication support. These also addressed constraints of time and geography, which would have hindered participation for some participants and put undue burden on [initials]. It also reduced some of the inherent biases in recruiting participants with speech impairments or no verbal communication, known to compromise eligibility in communication (Parkes, Donnelly, McDowell, & Duffy, 2012).

[Insert Table 1].

Recruitment was voluntary, so if individuals were interested to participate in the study they contacted the research team themselves. After this they were sent a recruitment questionnaire

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3 (electronically) to establish whether they met the inclusion criteria, describe their impairment
4 type and the effects of their impairment (e.g. mobility, speech, co-ordination) and to ascertain
5 their preferred method of interview. Individuals who met the inclusion criteria were given
6 more detailed information about the study, and a consent form. Once the research team had
7 received completed recruitment questionnaires and signed consent forms, appointments were
8 arranged to interview each participant.
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11 Ethical approval

12 Ethical approval was granted by the [insert later] Ethics Committee and the HRA [insert
13 later]. All participants gave both written and verbal consent. Participants chose their own
14 pseudonyms.
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18 Data Collection

19 Interviews with women took place between November 2019 and August 2020. Ten
20 interviews were in-person, three were conducted over the telephone and twelve using digital
21 methods (Skype, Facebook instant messenger or email). The in-person interviews were
22 conducted in places accessible and convenient for the participants, including in their home or
23 a café, or in an office at the University. All interviews were recorded, with the participants'
24 consent. In-person, telephone and Skype interviews were transcribed. A transcript was
25 generated automatically for the email and instant messenger interviews. Copies of the
26 interview transcripts were offered to the participants where they could not access them
27 automatically.
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31 A topic guide was designed to explore several themes with the participants. These included
32 perceptions of keeping healthy, and the behaviours adopted and support structures utilised to
33 do this; experiences of cervical smears, mammograms and sexual and reproductive health
34 across the life course, including examples of good and poor practice; and experiences of
35 growing older with CP, particularly embodied and lifestyle effects.
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38 Data analysis

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40 Two members of the study team independently analysed all the interview transcripts using a
41 framework analysis approach (Ritchie, Lewis, McNaughton-Nicholls, & Ormston, 2013;
42 Ritchie & Spencer, 2002). Ritchie and Spencer (2002) outlined five stages of framework
43 analysis, which we used as a guide: *Familiarisation, Identifying a framework, Indexing,*
44 *Charting, Mapping and Interpretation.*
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47 At weekly meetings and often daily emails we discussed and confirmed the themes generated
48 from the analysis, and agreed on meaningful codes and sub-codes, or concepts, that clearly
49 described the emergent data developed to form the matrix. The research team comprised two
50 nurses and one specialist on disability issues. All are experienced qualitative researchers.
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53 Rigour

54 We integrated a number of strategies to augment the rigorous conduct of the study. As
55 discussed [insert initials] undertook all the interviews, but to ensure that the analysis and
56 interpretations were grounded in the data, the transcripts and emerging interpretations were
57 shared with the team. The study design and conduct were informed by an advisory committee
58 and this external scrutiny of experts by experience was invaluable in checking out and
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3 verifying the findings of the study. Crucially, this increases the chances that the findings and
4 recommendations are relevant to practice.
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6 FINDINGS

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8 Twenty-five women who identified as having CP were recruited into the study. The
9 participants were based in England, Scotland, Wales or Northern Ireland and were within
10 distinct age cohorts, corresponding to the temporal stages of the female life cycle: ages 14-17
11 (teenage years - puberty/menarche), 18-35, 36-54 (young and middle adulthood - fertility,
12 family planning and pregnancy), and 55 and above (older adulthood - menopause and post
13 menopause). **Six participants classified their CP as hemiplegia, eight as diplegia and 11 as**
14 **quadriplegia.** Tables 1 and 2 show the proportion of participants in each age cohort, and how
15 **they were dispersed across the** the four countries in the UK.
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19 [Insert Tables 2 and 3]

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21 Analysis of the data revealed several themes. Three of these are relevant to nursing in
22 particular and are reported in this paper according **to a priori headings related to the**
23 **questions we sought to answer about women-centred screening programmes.** These are 1)
24 Barriers to sexual health checks, 2) Enablers to sexual health checks, and 3) **Participants'**
25 **suggestions for change, to improve future practice.**
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28 Theme 1: Barriers to sexual health checks

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30 Women's participation in **screening programmes** was influenced by physical and
31 environmental barriers, and fear that the invasive procedure would be too uncomfortable in
32 combination with the effects of their impairment as HCPs do not have the relevant specialist
33 knowledge and understanding of the effects of CP for adult women in order to make it more
34 accessible. Four of the women, in young and middle adulthood, expressed concern that the
35 **cervical screening** procedure would be too uncomfortable for them. Women either opted out
36 completely or delayed the check:
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39 *I know it will be difficult to do speculum examination on me so I opted out. I also know*
40 *my risk of HPV infection is low. (Violet, middle adulthood, **diplegia**)*

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42 *I had quite bad spasms intimately, so that stopped intercourse because it's really*
43 *painful but secondly, it's why I won't go for smears. (Eididh, middle adulthood,*
44 ***diplegia**)*

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47 *I have no need for a smear test yet, but when the time comes I am worried how the*
48 *procedure would be carried out due to my spasticity. (Ellie, young adulthood,*
49 ***quadriplegia**)*
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52 Women suggested that not all HCPs understood the effects of their impairment and how it
53 might impact and be impacted by the cervical smear procedure, so were not aware of the
54 extra time and resources that may be necessary. For example, Rose was 29 at the time of
55 interview and had not had a smear test. She recalls experiencing different challenges, in
56 relation to screening procedures, with two medical practices:
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My last one didn't really acknowledge that at all, and it didn't get mentioned, but this one... I haven't had a smear test yet, but they're, like, trying to find ways of how they can accommodate me at the surgery... I do remember one nurse that wasn't very good. I had my new patient medical and the nurse that did it asked me about smear tests and I said I hadn't had one and I tried saying some of my concerns, like the spasticity and opening my legs and things and she was very dismissive she was like 'well if you can have sex, you can do it', and that was it. That was all she said. (Rose, young adulthood, quadriplegia).

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Eventually though the HCPs from the second practice did work with Rose to find suitable ways for her to undergo the procedure comfortably.

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Gemima, who was 45 with quadriplegia could not undergo **cervical screening** in the conventional way, due to the level of spasticity in her legs, and the spasms triggered by the invasive procedure. However, both her and her mother were very aware of the importance of regular sexual health checks for women, especially when they were as sexually active as Gemima had been since the age of seventeen. After the first **test** was unsuccessful, she has had subsequent **cervical screening** under general anaesthetic, which was arranged by her GP. Although this was good practice, she does feel that her sexual health as a disabled woman was not taken seriously, and influenced by the assumption of her being asexual:

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I can't have smear tests normally, I have to go into hospital and get general anaesthetic because my legs are tight at the top so I can't open my legs, so I have to be taken into hospital. And the last time I was in, the guy that did it said to me after it 'I think next time we'll wait five years rather than three years.' Which he shouldn't have done that because I think up until you're fifty it should be every three years and after that every five... But obviously he didn't ask me about my sex life so I don't know if maybe he assumed I wasn't having sex so it didn't matter (Gemima, middle adulthood, quadriplegia).

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The six women that were over the age of 50 all had all had at least one mammogram up to the time of interview, some had had two. Women's experiences of mammography were mixed. Linda describes the difficulty she experienced trying to balance and keep her body still while the procedure was performed:

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I have had one before because I had a suspected lump, turns out it was just a cyst, but that was quite difficult because with my balance and the pressure from those machines would knock you on your back and I told the nurse during that process (Linda, older adulthood, hemiplegia).

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Rayaana recalls the challenges experienced during her first mammogram which could have been prevented had she been listened to by the mammography staff. She identified herself as having quadriplegia CP and has a speech impairment. She does walk **short distances**, and also uses a power chair for mobility:

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The first mammogram... I said to them 'I need to get out my wheelchair to steady my body' they said 'no, no, it's easier for us if you stay in' like I'm nothing, like I don't have a say... They nearly took my breasts off! Don't laugh! I have more control when I sit on a normal chair. And they said it's quicker if you stay in your wheelchair and I couldn't keep my body steady. So, my tits were clamped in the machine and I moved

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3 *when my breasts were still clamped. I told them ‘don’t call me, I won’t be coming*
4 *back’. I made a complaint (Rayaana, older adulthood, **quadriplegia**).*
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7 Despite the challenges, the majority of the women felt it was important to have regular
8 **women-centred screening** to stay healthy, even though **could be** uncomfortable and
9 painful, **and cause them to spasm**. For example, Sophia Appleby and Kathleen (of
10 different ages) describe what it is like to have a **cervical** test with their impairment, and the
11 support and perseverance necessary to ensure it is successful:
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14 *I go for every smear test that I’m invited to go to, I go for and they’re so difficult, but I*
15 *go for them every time because I think it’s important...it just takes so long and without*
16 *being graphic, my cervix is quite far up and tucked away so it’s difficult to find my*
17 *cervix anyway. I went for one about two weeks ago and I had one person on each leg*
18 *holding my legs apart because I can’t hold them apart and I had two health care*
19 *professionals looking down at me, with the light and it took twenty minutes to find my*
20 *cervix (Sophia Appleby, young adulthood, **diplegia**).*
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22
23 *Going for a smear tests is a pain in the backside because you’ll get shouted at because*
24 *you can’t open your legs wide enough, or you can’t do this. They’ll say, ‘why can’t*
25 *you’ and it’s just like, ‘I can’t, I physically can’t do it’ and you have to explain*
26 *beforehand and that can be quite frustrating at times because there just isn’t enough*
27 *knowledge about the condition at all (Kathleen, middle adulthood, **diplegia**).*
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29 Theme Two: Enablers to sexual health checks

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31 As indicated in the previous theme, in general older women with different types of CP had
32 positive experiences of mammograms. Even where the first mammogram was challenging,
33 the barriers seem to be broken down by the time the women had their second. For instance,
34 Rayaana who, as a result of making a complaint after her first mammogram, had a positive
35 experience during the second:
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38 *Last year, my mammogram was perfect. Total attitude change, new machines and they*
39 *let me get out [of my wheelchair], they listened to me. It was worth putting my foot*
40 *down (Rayaana, older adulthood, **quadriplegia**).*
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43 Poppy who also has a speech impairment, explained how both of her mammograms have
44 been positive as the environment was accessible and the staff had been trained to
45 accommodate her physical needs. She recalls a similar experience with her smear test:
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48 *I had my last breast screening 5 years ago, 2015 I have had 2 altogether. There were 2*
49 *female nurses at both appointments. I requested a longer appointment for the second*
50 *screening which helped me relax. My local breast screening unit is wheelchair*
51 *accessible and I was able to use my mobility scooter for the second appointment which*
52 *was easier. Parking was good but still quite a distance for me to walk.*
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55 *My best appointment was a smear test at my local GP. The nurse was patient and*
56 *friendly. She asked if I needed any help and then left me to get on with undressing. She*
57 *was very gentle and didn’t hurt me at all – this was very unusual for me, I usually leave*
58 *the surgery in pain! I think it was her manner that made the appointment so good*
59 *(Poppy, older adulthood, **quadriplegia**).*
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Barbara is a full-time wheelchair user, based in Wales. She recollects how, over her life course, the **screening procedures** she has had have been positive in terms of staff attitudes and equipment, exemplifying good practice:

*I go for regular smear tests and I go to the local GP surgery and, touch wood, up to now, the nurses there have always been very understanding... I stayed in my wheelchair and the [mammogram] machine comes down to the level of the wheelchair (Barbara, older adulthood, **quadriplegia**).*

Rachel has hemiplegia, thus mobility is difficult, as is positioning of one arm. She recalls how she had the opportunity to voice her needs prior to the mammogram, making it a better experience than it might have been had this not been an option:

*I didn't like the idea of trying to get up one of those silly caravan steps into one of them caravan things. So, I spoke to the GP because the letter says 'if you have a disability that may cause you issues, ring this number.' And I did and I explained and I said 'look, I don't really want to have to go...' so I have mine down at the QE. I've had two done now and it is difficult because of the position, like, my arms in and I'm saying the same thing to like the mammogram person...And they're pretty good you know. (Rachel, older adulthood, **hemiplegia**).*

However, in general the women who chose to participate in **screening programmes** reported mixed experiences of these across their lives. They suggested this was largely dependent on HCPs' level of knowledge and understanding of impairment effects for women with CP, as well as their ability to listen to the women in relation to what they need to successfully participate in screening procedures.

Theme Three: Suggestions for change

To end each research interview participants were asked to suggest one or two things that they believed could be changed to improve experiences of **screening programmes** for women with CP. The first message from participants was for an understanding **and** awareness of **CP amongst HCPs** and services for adults with CP.

*There are so many people now with cerebral palsy it isn't as if there isn't that many of us, and I just think there isn't the knowledge. In Northern Ireland there isn't one specialist on adult cerebral palsy which, you know, is very frustrating. There is nobody who you can go to talk to, there is no one to just sit down and advise you, 'as you get older, this could happen, that could happen.' And it's just finding out for yourself which is a big shock sometimes (Elizabeth, middle adulthood, **quadriplegia**).*

*I would like people to actually research more about it, like the doctors and stuff...to warn you when you're younger that tells you cerebral palsy does change...just to warn you to be aware of everything that happens and just don't take anything for granted because it could all change tomorrow like it did for me (Gemima, middle adulthood, **quadriplegia**).*

Participants emphasised repeatedly that services for **people with CP** were generally geared towards children. Moreover, that HCPs need to understand the effects of CP across the life course, with many impairment effects deteriorating as women aged.

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3 *I had my abductors cut when I was twelve so my legs are quite loose but I have a*
4 *friend with CP and hers are very, very tight and I think that they just need to*
5 *understand that you can't always open your legs, you can't always put them in the*
6 *position that they need them to be in. There is a big lack of that understanding*
7 *(Barbara, older adulthood, **quadriplegia**).*
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10 This went hand in hand with a strong message that there should be better education and
11 training about adult CP for HCPs:
12

13 *Better education about CP for front line carers and workers whether that is at a GUM*
14 *clinic, whether that's a GP whether that's a midwife...less focus on their health and*
15 *safety policy and more about their person-centred care policy (Ellie, young*
16 *adulthood, **quadriplegia**).*
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18

19 Participants also said that there was a dire need for joined-up **screening** services with
20 specialist knowledge of CP.
21

22 *An in-between service that could provide us with some support, whether it be to do*
23 *with going for your smear tests or pregnancy or, kind of an intermediate between the*
24 *health services so you kind of aren't walking into a room and having to explain*
25 *yourself and them go: 'well, I haven't got a clue because you've got cerebral palsy.'*
26 *(Kathleen, middle adulthood, **diplegia**).*
27
28

29 Other participants suggested having a specialist nurse for CP to provide ongoing support for
30 people with CP across the life course. Their role would be to ensure a smooth transition
31 between paediatric and adult health services for individuals with CP, offer direct support and
32 clinical advice to patients about ongoing and new health needs, and connect patients to
33 appropriate health services and ensure the necessary accommodations are in place for the
34 patient during the visit.
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37 **[Insert Table 4]**
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41 DISCUSSION

42 **The findings from this study are represented in Table 3. This shows how both the enablers**
43 **and barriers are juxtaposed and both are influenced (either positively or negatively**
44 **respectively, by education of HCPs and joined up, responsive services. Our findings highlight**
45 **how physical and environmental barriers contributed to the low uptake of regular preventive**
46 **sexual health checks (Table 4). This supports findings from a study in the UK by Jo's**
47 **Cervical Cancer Trust (2019) found that many disabled women were prevented from having**
48 **regular checks due to being unable to enter the GP surgery in their wheelchair, or because the**
49 **examination table is static so cannot be adapted to accommodate their physical needs. Mele,**
50 **Archer, and Pusch (2005) found, from their study with women with physical impairments**
51 **(including CP), that women felt devalued by HCPs and believed their symptoms were**
52 **overlooked. Although women with CP face similar barriers to other disabled women in**
53 **relation to **women-centred screening programmes**, they are also likely to experience barriers**
54 **caused by HCPs' lack of understanding of the effects of CP in adulthood and how these**
55 **interconnect with the female life cycle (Table 4). For example, the invasive nature of cervical**
56 **examinations may trigger spasms or additional pain for women with CP (Fasen et al., 2020),**
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3 or the involuntary movements associated with some types of CP could cause the breast to be
4 overshadowed by the head and shoulder thus preventing the clear visualisation of breast
5 tissue (Poulos et al., 2006). Spasticity is disagreeable, complex and little understood
6 (Bhimani, McAlpine, and Henly 2012), but listening to women's own words about it can be
7 helpful. These challenges contribute to the underutilisation of screening by women with CP.
8 Evidence suggests that although mammography can significantly reduce the incidence of
9 breast cancer, its underuse by disabled women leads to a delay in diagnosis of breast cancer
10 and a less favourable long-term outcome compared to non-disabled contemporaries (Poulos
11 et al., 2006).
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15 Although many of the structural problems can be overcome by alternative screening methods,
16 such as smear tests under anaesthesia or mammograms using ultrasound, the perceived
17 inconvenience of this, to women and practitioners, is likely to lead to screening being
18 deferred at best (Ramjan et al. 2016) **and avoided completely at worst**. The implementation of
19 such alternative procedures requires positive attitudes from HCPs, including an enhanced
20 knowledge and understanding that disabled women are sexual beings (Jones et al. 2017;
21 Shah, Tsitsou, and Woodin 2016).
22
23

24 The **screening** care of women with CP (as with disabled women in general) is equally
25 important to that of non-disabled women. Without such knowledge and understanding,
26 disabled women will continue to have poor access to family planning services, providing
27 knowledge and counselling regarding contraceptives and preparing for pregnancy (Taouk,
28 Fialkow, & Schulkin, 2018). In a study on disabled women's transition to motherhood,
29 women were shown to utilise a range of emotion and problem focused strategies to manage
30 their lives (Lawler, Begley, & Lalor, 2015). Without adequate understanding of the
31 perspectives of women with CP (and disabled women more generally), we would argue that
32 nurses and other HCPs are not adequately equipped to provide best care to this group of
33 women.
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37 There (rightly) has been an increased emphasis on issues of equality and diversity in recent
38 years, reflected in (for e.g.) the International Council of Nurses (2016) position statement on
39 Nurses and Human Rights. However, evidence suggests that on the whole there is limited
40 training, within healthcare curriculums, about the biological and social experiences of women
41 with CP and other lifelong impairments and therefore a lack of awareness, confidence and
42 knowledge among qualified HCPs to provide good quality care to this population (Willis &
43 Thurston, 2015). The National Institute for Health and Care Excellence (NICE) (2019) has
44 specifically recommended a care pathway for adults with CP which includes access to
45 advocacy support, improved physical access, and communication skills training for HCPs –
46 amongst many others. It does not yet seem that awareness of and adherence to such guidance
47 is commonplace.
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51 **As shown in Table 4, the presence or absence of HCP education in relation to CP can affect**
52 **care positively or negatively**. Enhanced knowledge and awareness of the impairment effects
53 for women with CP, and how environments and procedures can be adapted to accommodate
54 their needs, and thus increase their participation, is sorely needed. Such knowledge can
55 contribute to reducing the current inequalities to accessing and utilising sexual health checks
56 for women with CP; and inform the development of new measures to increase their
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3 participation rates in routine screening, and reduce risk of preventative mortality among
4 populations of disabled women.
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6 7 **Limitations**

8 The study was conducted with 25 women who identified as having a diagnosis of CP. This
9 self-selecting group of women may have come forward to participate in the study because
10 they had personal, negative experiences of healthcare that they wanted to voice. This may
11 mean that some of our findings point predominantly to the barriers experienced by the
12 women who took part and **should not be seen as being representative of all women with CP.**
13 However, this is tempered by their positive accounts and suggestions for improved
14 healthcare. We were pleased to recruit so many women to this qualitative study because we
15 gained considerable insights into their experiences of **screening programmes for women.**
16 However, there are some findings that warrant further information, such as the specific
17 challenges around cervical and breast screening.
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22 **CONCLUSION**

23 The findings reported in this paper, from service users, can inform the design of new clinical
24 guidelines and practices that accommodate the needs of women with CP, thereby increase
25 their participation rate in screening and reducing unfavourable preventative health risks. It is
26 important that HCPs are educated and supported in practice to provide appropriate care for
27 women with CP.
28

29
30 [We] are also concerned at the increasing rollback and regression on respect for
31 international human rights norms that threaten sexual and reproductive health and rights
32 of women, including women with disabilities, who continue to experience intersecting
33 forms of discrimination (Committee on the Rights of Persons with Disabilities (CRPD)
34 and the Committee on the Elimination of Discrimination against Women (CEDAW),
35 2018).
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40 **Impact:**

41 Knowledge of the challenges to sexual health checks experienced by women with CP across
42 the life course is crucial. This is because it acts as a springboard from which women can plan
43 for, and health providers can develop, strategies to provide appropriate preventative sexual
44 health care for women with CP across different stages of life. Elements of this knowledge
45 could have benefits for the care of all disabled women and it is suggested that healthcare
46 curricula integrate the opportunity for learning about this important issue.
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- 50 • **What problem did the study address?**

51 The study addressed the paucity of available evidence regarding barriers and enablers to
52 sexual health checks for women with CP.
53

54 The study provided insights into the hitherto unheard voices of women with CP about their
55 experiences of sexual health checks.
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57

- 58 • **What were the main findings?**

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3 Access and utilisation of **women-oriented routine screening** for **those** with CP across the life
4 course is determined by multiple socioecological factors.
5

6
7 Practitioner attitudes and understanding about the effects of CP for adult women is a potential
8 barrier to good quality healthcare for women with CP.
9

10 Women's experiences and uptake of preventative sexual healthcare is influenced by the
11 accessibility and adaptability of the environment and procedures.
12

13
14 • **Where and on whom will the research have impact?**

15
16 Understanding the lifelong effects of CP for women, and the interaction with **preventive**
17 **screening** will help to reduce unmet healthcare needs for women with CP.
18

19 Health providers can develop strategies to provide appropriate **preventative routine screening**
20 for women with CP across different stages of life.
21

22
23 Informed HCPs and supportive healthcare environments will have benefits for the care of all
24 disabled women, meaning that the study findings are likely to have transference beyond the
25 specific context of women with CP.
26

27
28 **Conflict of Interest Statement:**

29 No conflicts were reported
30

31
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47 *health and rights for all women, in particular women with disabilities*
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- 49 Joint statement by the Committee on the Rights of Persons with Disabilities and the Committee on
50 the Elimination of All Forms of Discrimination against Women *Available at:*
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Table 1: Diagnostic Labels

Diagnostic Labels	Body part affected	Effects
Quadriplegia	4 limbs	Muscles and coordination in both arms and legs; sometimes muscles in trunk, face and mouth
Diplegia	2 limbs	Usually both legs; Arms may be, but to a lesser extent.
Hemiplegia	One side of the body	Muscles and co-ordination in one arm and leg


Table 2: Ages of participants

	Life Stage	Participants
14-17	Teenage	1
18-34	Young adulthood	11
35-54	Middle adulthood	7
55+	Older adulthood	6

Table 3: Countries of participants

UK Country	No. of participants
England	18
Scotland	4
Wales	2
Northern Ireland	1
Total	25

Table 4: Experiences of routine screening for women with CP.

Barriers	Enablers
Restrictive Environment Physical impairment related difficulties Fear and anxiety Negative HCP attitude	Appropriate technologies Positive HCP attitude
	
Suggestions for Change	
HCP education Joined up, responsive services	