

Appendices

Appendix A: Letter of Ethical Approval



College of Health, Medicine and Life Sciences Research Ethics Committee (DHS)
Brunel University London
Kingston Lane
Uxbridge
UB8 3PH
United Kingdom
www.brunel.ac.uk

19 January 2021

LETTER OF APPROVAL

APPROVAL HAS BEEN GRANTED FOR THIS STUDY TO BE CARRIED OUT BETWEEN 15/12/2020 AND 21/04/2021

Applicant (s): Miss Lindsay Maclsaac

Project Title: Knowledge Gaps and Acquisition of Information Related to Pelvic Floor Dysfunction in Young Nulliparous Females

Reference: 26070-MHR-Jan/2021- 29702-3

Dear Miss Lindsay Maclsaac

The Research Ethics Committee has considered the above application recently submitted by you.

The Chair, acting under delegated authority has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- Participant Information Sheet: Before sending out to participant Please change "taking a screenshot" under "Do I have to take part?" to: If you wish to keep a copy of this participant information sheet, you may wish to save it on your computer or smart device, or email xxx insert your email xxx for a copy'. and ask your supervisor to check
- **Approval is given for remote (online/telephone) research activity only. Face-to-face activity and/or travel will require approval by way of an amendment.**
- **The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee by way of an application for an amendment.**
- In addition to the above, please ensure that you monitor and adhere to all up-to-date local and national Government health advice for the duration of your project.

Please note that:

- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the relevant Research Ethics Committee.
- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the relevant Research Ethics Committee.
- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.
- The Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.
- You may not undertake any research activity if you are not a registered student of Brunel University or if you cease to become registered, including abeyance or temporary withdrawal. As a deregistered student you would not be insured to undertake research activity. Research activity includes the recruitment of participants, undertaking consent procedures and collection of data. Breach of this requirement constitutes research misconduct and is a disciplinary offence.

A handwritten signature in blue ink that reads "Christina Victor".

Professor Christina Victor


Chair of the College of Health, Medicine and Life Sciences Research Ethics Committee (DHS)

Brunel University London

Appendix B: Survey

Question 1


Exercising the pelvic floor muscles can help with pelvic floor problems. What are these pelvic floor problems?

A rectangular text input field containing a red 'X' icon, indicating that no answer was provided for this question.

Section Break

Question 2


Can you describe how to exercise the pelvic floor muscles?

A rectangular text input field containing a red 'X' icon, indicating that no answer was provided for this question.

Section Break

Question 3


Have you had any personal experience with pelvic floor problems?

A rectangular text input field containing a red 'X' icon, indicating that no answer was provided for this question.

Section Break

Question 3.1


If you feel comfortable sharing, what have you experienced and how have you dealt with the issue(s)?

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Section Break

Question 4


What bladder symptoms can you get if your pelvic floor muscles are not working properly?



Section Break

Question 5


What bowel symptoms can you get if your pelvic floor muscles are not working properly?



Section Break

Question 6


Have you heard of the term Pelvic Organ Prolapse? If so, what do you know about it?



Section Break

Question 7


Does the pelvic floor play a role in sexual pleasure? If so, how?



Section Break

Question 8

Some women experience symptoms of leaking urine. What is your experience with this?




Do you know of any ways to treat urine leakage? Please explain.



Section Break

Question 9


Some women suffer with an uncomfortable sensation of something in their vagina, such as a heaviness or bulging sensation. Do you know what is causing this and what you can do to prevent this from happening?



Section Break

Question 10


Where has your knowledge about pelvic floor problems come from? *E.g. school health class, university course, media (what type?), relative, etc.*




Section Break

Question 11

Pelvic floor dysfunction can be a hard subject to discuss. How would you like education about this subject? (For example, high school sex-education, social media ads, leaflets at doctor's offices, etc.)




Why do you think this method(s) would be best?




Section Break

Question 12

When (if ever) do you think women should start learning about pelvic floor dysfunction?




Why?



Section Break

◇ Question 13

Do you want to learn more about the pelvic floor?



Section Break

13.1 - Resources

You selected Yes, please see the following NHS links for more information on the pelvic floor:


- ▣ Pelvic Organ
- ▣ Prolapse: https://thepogp.co.uk/patient_information/womens_health/vaginal_prolapse.aspx Bladder & Bowel
- ▣ Incontinence: https://thepogp.co.uk/patient_information/womens_health/bladder_bowel_incontinence.aspx
- Pelvic floor muscle exercise: <https://pogp.csp.org.uk/publications/pelvic-floor-muscle-exercises-women>

These links are for your personal knowledge and are not associated with this survey.

Section Break

◇ Question 14

Do you have anything else to add?



Section Break

Thank you for participating in this survey. Your responses have been recorded.

Appendix C: Facebook Post

The screenshot shows a browser window with the address bar displaying 'facebook.com'. Below the browser window is a Facebook sharing interface. At the top, there is a blue bar with the Facebook logo and the text 'Share on Facebook'. Below this is a white bar with a dropdown menu labeled 'Share in a Group'. The selected group is 'Dissertation Survey Exchange'. The post content is from user 'L.E.MacIsaac' and contains the following text:

Looking for FEMALES, aged 18-27, who have NOT had children (and are not pregnant to their knowledge).
Researching the knowledge of the pelvic floor in young women without children. All knowledge levels are encouraged to participate and responses will remain anonymous.
Please post a screenshot in the comments of my completed survey & a link to yours for me to complete.
This research is part of my MSc at Brunel University London and has been approved by the College of Health, Medicine and Life Sciences Research Ethics Committee. Approval date: 01/19/21. Expiry/End date: 04/21/21

Below the text is a promotional banner for 'BRUNEL.ONLINESURVEYS.AC.UK Women's Pelvic Floor Knowledge Online survey BOS'. The banner features a logo of two overlapping speech bubbles, one green and one blue. Below the banner are three icons: a person with a plus sign, a location pin, and a smiley face. At the bottom, there are two radio button options: 'News Feed' (selected) and 'Your Story'. A blue bar at the very bottom contains a 'Cancel' button and a 'Post to Facebook' button.

Appendix D: Content Analysis

Question	Codes	Categories	Themes
Pelvic floor muscle dysfunction	<p>Q9</p> <ul style="list-style-type: none"> Weak (3/51) Tension/ relaxation (5/51) Able to identify PFDs <ul style="list-style-type: none"> POP (3/51) Urinary dysfunction (26/51) Sexual dysfunction (4/51) Pain (6/51) Bowel dysfunction (4/51) Causes <ul style="list-style-type: none"> Pregnancy (7/51) Older age (2/51) Incorrect Don't know (10) <p>Q10</p> <ul style="list-style-type: none"> Equipment (4/51) Correct engagement (18/51) <ul style="list-style-type: none"> "clench and then relax", "pull in ... relax", "expand and squeeze", "stop peeing then relax", "flex and relax", "squeeze... periods of time or do intervals", "squeezing", "stop and start during urination", "pull "up" your insides", "squeeze and release... X and O's", etc. Unsure (10/51) Kegel mentioned (11/51) <ul style="list-style-type: none"> 9/51 mentioned kegel but did not describe 2/51 described it Unrelated/ indirect exercise (10/51) <ul style="list-style-type: none"> 5 responses mentioned bridging (but none referenced how to engage the pelvic floor) Others include "exercises which train balance"(1), "slow hip rotations? (1) Stretching"(1), "squats" (3), "lunges"(1), "push ups"(1), "horse riding"(1), "dancing"(1), "yoga" Pilates (3/51) 	<p>Awareness of UI</p> <p>Attributing PFD to causes not related to young nulliparous women</p>	<p>Acknowledgement of UI</p> <p>Lack of knowledge of Other PFDs</p> <p>Lacking acknowledgement of PFD in young nulliparous women (ie, absence of pregnancy, older age, etc.)</p> <p>Normalisation – kegels/ pelvic floor muscle activation</p> <p>Need for educating females about their bodies</p>
Experience with PFD	<p>Q11</p> <ul style="list-style-type: none"> 4 respondents selected yes <p>Q12</p> <ul style="list-style-type: none"> Responses included "stress incontinence", "slight incontinence", "repeated UTIs... pelvic floor dysfunction", "constipation" 		
	<p>Q17</p> <ul style="list-style-type: none"> An additional 5 respondents (aside from the 4 in Q11) reported symptoms of leaking urine 	Potentially normalising leaking urine as women.	Negative impact of normalisation
POP	<p>Q15</p> <ul style="list-style-type: none"> Have heard of POP (11/37) <ul style="list-style-type: none"> Of that number, 6 were somewhat able to explain it 2 incorrectly explained it including "internal organs, your intestines (?) fall out of your bunhole" and "where you tear, commonly from your vagina to your anus" 1 identified it as related to elderly 1 identified it as related to post-partum women 1 said mother has it but doesn't know about it <p>Q19</p> <ul style="list-style-type: none"> Identifying the problem <ul style="list-style-type: none"> 4/36 labelled it as POP 5/36 labelled it as other things <ul style="list-style-type: none"> Including "ovary cysts", "menstruation", "tensing", "attempting to relax those muscles, sitting on the toilet, exercising", "cysts on the ovaries" 5/36 responses for prevention <ul style="list-style-type: none"> Including "pelvic floor exercise", "kegels", "GP or access medical care" etc. 	<p>General lack of understanding around POP</p> <p>General lack of understanding around POP</p> <p>POP treatment understanding in those that could identify it</p>	<p>Lacking knowledge of other PFDs – POP</p> <p>Lacking Acknowledgement of PFD in Young Nulliparous Women</p>
Urinary Dysfunction	<p>Q13</p> <ul style="list-style-type: none"> Able to identify at least 1 bladder symptom related to PFM (30/37) <ul style="list-style-type: none"> Responses included "incontinence" / "stress incontinence" (23), increase frequency/ overactive bladder (8), pain/ burning symptoms (3) Of those, five were able to identify 2, one identified 3 and one identified 4 <ul style="list-style-type: none"> Overactive bladder (1), pain (1), urinary retention (2) <p>Q18</p> <ul style="list-style-type: none"> Surgery (3/36) <ul style="list-style-type: none"> Surgical reference x3 Vaginal mesh/ Sling x2 PFME/pelvic floor therapy (15/36) Medication (2/36) Medical help (3/36) 	<p>General education regarding urinary dysfunction</p> <p>Acknowledgement of PFME as a rx for PFD</p>	<p>Acknowledgement of UI</p> <p>Lacking Knowledge of Other PFDs</p>

	<ul style="list-style-type: none"> Other <ul style="list-style-type: none"> “go to the bathroom”, “practice holding it”, “keeping warm”, “try not to drink a lot of water” Pads (6/36) 11/36 said they do not know any ways to tx urine leakage 	Lack of education on rx for PFD	
Bowel Dysfunction	<p>Q14</p> <ul style="list-style-type: none"> Prolapse (1/35) Constipation (10/35) Incontinence (7/35) Digestive related (3/35) Pain (1/36) Able to name 2 or more symptoms (2/35) 	<p>Attributing to other GI-related problems</p> <p>Lack of education re bowel dysfunction</p>	Lacking Knowledge of Other PFDs
Sexual Dysfunction	<p>Q16</p> <ul style="list-style-type: none"> Aiding orgasm (5/35) <ul style="list-style-type: none"> “Achieve orgasm”, “stronger orgasm”, “orgasm more/ multiple times” Other things referenced: <ul style="list-style-type: none"> “Muscle control” “More sensation” “Make you feel more confident” “Better grip and flexibility” “Last longer in bed” “If contracted/ tight can make sex painful or uncomfortable” Referencing relaxation (1/35) Referencing partner or the word “tighter” (6/35) <ul style="list-style-type: none"> “I have heard that they exercising the pelvic floor can increase sexual pleasure, but I am not entirely sure how or for whom. I assumed it would make the female feel ‘tighter’ for the male, but I am unsure how that would increase pleasure for the female.” Unsure if/how pelvic floor plays a role in sexual pleasure (14/35) Pelvic floor does not play a role in sexual pleasure (2/35) 	<p>Referencing female-centric pelvic floor importance in sexual pleasure</p> <p>Male-centric re female’s pelvic floor importance in sexual pleasure</p> <p>Gross lack of understanding on role of pelvic floor in sexual pleasure</p>	<p>Positive impact of normalisation</p> <p>The male gaze</p> <p>A Need for Educating Females about their Bodies</p> <p>Lacking Knowledge of Other PFDs</p>
Knowledge	<p>Q20 – where previously</p> <ul style="list-style-type: none"> Medical practitioner (5/36) <ul style="list-style-type: none"> Ie. doctor, friends who study medicine, nursing school, mum is a GP School/ health class (4/36) 		

	<ul style="list-style-type: none"> Online/ social media (15/36) <ul style="list-style-type: none"> “media when searching for tips on how to deal with period cramps” “podcasts e.g. happy mum, happy baby” “Instagram”, “tiktok” “learning online, nobody has ever taught me any of this” Family/friend (9/36) Other (4/36) <ul style="list-style-type: none"> “books”, “pilates”, “worked for a sexual health charity & magazines” Nowhere (3/36) <p>Q21 – how in future</p> <ul style="list-style-type: none"> School-age/ sex-ed (25/37) Social media (14/37) <ul style="list-style-type: none"> “Online information that is concise, easy to understand and find and is factual as i would not want to speak to anyone about these issues at all barring a close friend” Peer discussions (2/37) <ul style="list-style-type: none"> “Would be amazing to have sex education classes in high school talk to women about this more. So for example having all the female students have a class together where a bunch of myths about vaginas are discussed. Social media ads would also be great or like those Instagram infographics as they are so easy to share and can often reach A LOT of people.” GP related (11/37) <ul style="list-style-type: none"> E.g. “pamphlets at doctor’s office”, “info from gyno”, etc. “This would be great to learn about in doctor’s office pamphlets and also if it were talked about more online. I was very relieved when I was diagnosed because it gave me a solution to the issues I was facing... however, if you don’t know that pelvic floor dysfunction is a thing, you may have a difficult” <p>Q22 – why</p> <ul style="list-style-type: none"> Early learning/ preventative coding: “Talking about issues early”, “before getting pregnant”, “start early and reinforce later”, “teach girls about their bodies”, “comfortable envr for open discussion/questioning”, “get educated rather than hearing horror stories” Taboo/ Stigma: “not talked about enough and becomes taboo”, “needs to be normalized as something not be embarrassed about”, etc. 	<p>Online/ social media main form of learning currently</p> <p>School age/sexual education class large majority in future learning</p> <p>Non-face-to-face learning ie. Pamphlets, online etc.</p> <p>Early learning and prevention</p> <p>Taboo/stigma</p> <p>Accessibility to information</p>	<p>Importance of Early Education and Prevention</p> <p>Importance of Early Education and Prevention</p> <p>Positive impact of normalisation</p>
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	<ul style="list-style-type: none"> • Accessibility: "routinely teaching it in high school", "social media getting to the most people", "social media easy to access", "reaches audiences of all ages" <p>Q23 – when</p> <ul style="list-style-type: none"> • <10yrs = 1/36 <ul style="list-style-type: none"> ◦ Before adolescence • 10-12 yrs = 7/36 <ul style="list-style-type: none"> ◦ "when they're old enough to learn about sex education in school" – starts at age 11 in UK ◦ "When I learned about periods" • 13-14yrs = 10/36 <ul style="list-style-type: none"> ◦ Teenage ◦ Highschool when referencing "young" and not referencing uni • 15-16 (orange) = 7/36 <ul style="list-style-type: none"> ◦ Highschool + mentioning uni ◦ Late teens • 17+ = 2/36 • Other: Never, when they have problems with it, (2/36) • Uninterpretable/not answering question of when = 7/26 <ul style="list-style-type: none"> ◦ "yes", "it should be known generally", "any age", "young age", "as young as possible", etc. <p>Q24 – why</p> <ul style="list-style-type: none"> • Early learning/ prevention coding <ul style="list-style-type: none"> ◦ "It is important for them to know about their bodies early so they are aware of signs and symptoms and what they can do to help" ◦ "so they have the knowledge and know what to do if issues occur" • Taboo/ stigma <ul style="list-style-type: none"> ◦ "so the stigma is removed and younger generations are aware" • Understanding their bodies/ learning anatomy <ul style="list-style-type: none"> ◦ "They should understand how their body works and what's "normal" and what they can expect" • Pregnancy related <ul style="list-style-type: none"> ◦ "preparing them for changes during pregnancy" ◦ "...plenty of young women and teens who will become pregnant whether by accident or choice for many they'll never have been told some of the more unpleasant aspects of pregnancy... prevent or treat and pelvic difficulties..." 	<p>Early learning/ prevention</p> <p>Normalising: Taboo/stigma</p> <p>Educating females on their bodies/anatomy</p> <p>Educating women on their bodies</p> <p>Other risk factors Lack of understanding in nulliparous women</p>	<p>Importance of Early Education and Prevention Positive impact of normalisation</p> <p>A Need for Educating Females about their Bodies</p> <p>Lacking Acknowledgement of PFD in Young Nulliparous Women (ie. in absence of pregnancy / older age)</p>
	<p>Q25 – further learning</p> <ul style="list-style-type: none"> • 77.4% wanted to learn more about the pelvic floor (41/53) • 22.6% did not (12/53) 		

Appendix E: Survey Route and Survey Route Error

