**Appendix 1:** **Patient Questionnaire**

**For recruiter/principal investigator to complete:**

**Date of recruitment:**

**Hospital UR #:**

**Where has this patient been recruited from? Please circle**

* Gynae 1 clinic
* Gynae 2 clinic
* Post-op clinic
* Chronic pain clinic
* Via phone

**How has a diagnosis of endometriosis been confirmed? Please circle**

* As per patient – date and place of laparoscopy \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* As per referring clinician – date and place of laparoscopy \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Diagnosed via laparoscopy at the RWH – date of laparoscopy \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Other:

**What stage of endometriosis has been identified? Please circle**

* Stage I
* Stage II
* Stage III
* Stage IV
* Not known

**The Prevalence and Impact of Social Media to Seek Support and**

**Health Information in Women with Endometriosis**

**Instructions for participants:**

Thank you for participating in this study.

Please read and accept the patient information and consent form (PICF) prior to commencing.

Please complete the following questionnaire and return it in person to the Gynaecology 2 team box at the front of the Royal Women’s Hospital Gynaecology outpatient clinic. If completing online, please press submit at the end of the survey. If you encounter any difficulties please contact Dr Kelly van den Haspel (principal investigator of this study), details available in the PICF.

**Demographic Information**

1. What gender do you identify as?
2. What is your date of birth DD/MM/YYY?
3. What is your current marital status?
   1. Single
   2. Partnered
   3. Married
   4. Separated
   5. Divorced
   6. Widow
4. What is the highest level of education completed?
   1. No formal education
   2. Primary school
   3. Year 10 high school
   4. Year 12 high-school or equivalent
   5. University/TAFE
5. Are you currently working?
   1. Full time -> please go to Question 7. (add skip logic in survey monkey)
   2. Part time or casual -> please go to Question 7.
   3. Not working for pay
6. If not working for pay, is endometriosis a contributing factor?
   1. Yes
   2. No

**Health Information**

1. When were you first diagnosed with endometriosis?
   1. Within the last 6 months
   2. 6 – 12 months ago
   3. 1 – 5 years ago
   4. 5 – 10 years ago
   5. More than 10 years ago
2. What endometriosis symptoms do you predominantly suffer? You can tick more than one.
   1. Painful periods
   2. Heavy bleeding
   3. Infertility (unable to fall pregnant after 12 months of trying)
   4. Pain with sex
   5. Pain with using your bowels or bladder
   6. Pelvic pain for longer than 6 months
   7. Other, please specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
3. How long have you had pelvic pain for?
   1. Less than 6 months
   2. 6 months – 12 months
   3. More than 12 months
   4. I don’t have pelvic pain
4. How has your endometriosis been managed? You can tick more than one
   1. Surgical management e.g. laparoscopic (key hole) excision or ablation
   2. Pain medications e.g. Paracetamol, Non-steroidal anti-inflammatories, codeine, endone, tramadol
   3. ‘Atypical’ pain medications e.g. Endep, Lyrica, Gabapentin
   4. Hormone treatments e.g. the combined contraceptive pills, progesterone pills, Implant (Mirena or Implanon), Zoladex/Synarel
   5. Psychological treatment e.g. Cognitive behavioural therapy
   6. Non-medication treatment e.g. diet, exercise, heat, physiotherapy, complementary medicine
5. Have you experienced psychosocial impacts from endometriosis? You can tick more than one.
   1. Depression
   2. Anxiety
   3. Low self-esteem or body image
   4. Feelings of social isolation
   5. Embarrassment
   6. Emotional distress
   7. Relationship stressors
   8. Negative impact on your work/career
   9. None of the above
   10. Other, please specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Social Media Use**

1. Please select the statement that most accurately reflects your use of social media in general
   1. I access social media sites multiple times a day
   2. I access social media sites at least once a day
   3. I access social media sites once a week
   4. I access social media sites once a month
   5. I rarely access social media sites
   6. I never access social media sites
2. Have you ever used social media to seek health information or support for endometriosis?
   1. Yes
   2. No 🡪 **exit questionnaire**
3. How often would you access social media for health information/support for endometriosis?
   1. At least daily
   2. At least weekly
   3. At least monthly
   4. Less than once a month

**The following are descriptions an examples of social media platforms**

|  |  |  |
| --- | --- | --- |
| **Social media platform** | **Description** | **Example** |
| **Social Networking sites** | Online community platforms that allow users to connect and share interests and/or activities. | Facebook |
| **Blogs** | Platforms that allow users to post information, narratives or generate discussion |  |
| **Wikis** | Shared sites/platforms of collections of linked webpages that enable users to collaborate and coordinate information | Wikipedia |
| **Microblogs** | Short form of blogging that allows users to send brief information, short status updates or media to be viewed publicly or privately | Twitter  Tumblr |
| **Tagging/aggregation sites** | Allow users to save, collect, tag, manage and share links to web content (often in a centralised location). They sometimes also allow users to vote/rate content resulting in the most popular content being more visible on the site. | Digg  Reddit |
| **Video sharing sites** | Platforms that enable the publishing and sharing of video content | YouTube |
| **Photo sharing sites** | Enable the publishing and sharing of photo content | Instagram  Flickr |
| **Discussion forums/message boards** | Earlier social web technologies that enable users to post message and interact via message threads or topics (normally specific to an area of interest). |  |
| **Chat rooms** | Platforms that allow for synchronous communication between people, all online at the same time (they are normally specific to an area of interest). |  |
| **Virtual environments** | Simulated environments that allow users to interact with eachother and the surrounding environment | Second life |

1. Please tick the social media platforms you have used in relation to your endometriosis in the last 12mths:
   1. Social networking sites
   2. Discussion forums
   3. Blogs
   4. Wikis
   5. Video sharing sites
   6. Microblogs
   7. Photo sharing sites
   8. Tag/aggregators
   9. Chat rooms
   10. Virtual worlds

*In the following section you will be asked to provide detail in relation to those platforms you have used as part of your endometriosis self-management.*

1. How valuable is social media for information, communication or interaction about endometriosis?
   1. Not at all
   2. A little bit
   3. Somewhat
   4. Quite a bit
   5. Very much
2. How do you rate the quality of information on social media regarding endometriosis?
   1. Very poor
   2. Poor
   3. Average
   4. Good
   5. Very good
3. Please select the specific things you do on social media with regards to your endometriosis (you may select more than one):
   1. Status update
   2. Post to someone’s profile/page
   3. Like a comment or post
   4. Comment on someone’s post/content
   5. Tag content
   6. Private message
   7. Add friend/connection
   8. Chat
   9. Other (please specify):
4. Please tick the appropriate box that relates to these statements:

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Question | Strongly disagree | Disagree | Neither | Agree | Strongly agree |
| I have seen posts on social media regarding endometriosis |  |  |  |  |  |
| I have found helpful health information about endometriosis on social media |  |  |  |  |  |
| I have given/shared personal advice or stories regarding my endometriosis online |  |  |  |  |  |
| I have received advice regarding my endometriosis online |  |  |  |  |  |
| It helps me feel less alone when I see other women on social media discussing endometriosis |  |  |  |  |  |
| I feel supported when I see other women on social media discussing endometriosis |  |  |  |  |  |
| I like to connect/form relationships with other women suffering endometriosis on social media |  |  |  |  |  |
| I feel empowered seeing women share their stories on social media |  |  |  |  |  |
| I feel sad or upset by seeing other women’s stories about endometriosis online |  |  |  |  |  |
| Overall my experiences on social media with regards to my endometriosis have been positive |  |  |  |  |  |
| The best thing about social media and endometriosis is: | | | | | |
| I have had a negative experience on social media with regards to my endometriosis |  |  |  |  |  |
| Please describe: | | | | | |
| I have felt bullied or attacked when interacting with social media about my endometriosis |  |  |  |  |  |
| I use social media for health information/support more when my endometriosis is flaring |  |  |  |  |  |
| Social media has impacted my real-life decision making/treatment decisions |  |  |  |  |  |
| I frequently see misinformation about endometriosis online |  |  |  |  |  |
| I feel concerned regarding the quality of health information about endometriosis on social media |  |  |  |  |  |
| I worry about my privacy when engaging with social media about health information |  |  |  |  |  |
| Social media has raised public awareness and understanding of endometriosis |  |  |  |  |  |
| I would follow a hospital/medically run social media platform regarding endometriosis |  |  |  |  |  |

1. The best thing about social media and endometriosis is:
2. Please describe any negative experiences you have had on social media with regards to endometriosis
3. Please provide any other comments about social media use with regards to endometriosis

[Free text answer]

1. What information or services for endometriosis would you like to see provided by the hospital on the internet and social media?

[Free text answer]