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**EMA Transcript*****Narrator:***

Do You See Me Now is an exhibition held to communicate research findings on the impacts of endometriosis on patient quality of life. This art produced was in answer to the research question 'To what extent does Endometriosis, as a whole-body disease, impact upon the quality of life for sufferers in the UK?'.

I created six artworks which were shown alongside an installation created by medical simulation artist, Ren Hodges. Research findings were displayed in writing next to each artwork. The exhibition began with a short written piece and definition of endometriosis which reads as follows:

Endometriosis is a disease that is reported to be widely misunderstood and misdiagnosed. The National Health Service recently named Endometriosis as one of the top ten most painful conditions, defining it as 'long-term condition that can have a significant impact on your life'. Medically it's defined by the World Health Organisation as 'a disease where tissue similar to the lining of the uterus grows outside the uterus'. However, this definition does not consider the wider implications of living with endometriosis.

Having lived with endometriosis myself for over 15 years, I hope that these illustrations go some way to sharing the true impact of the disease on the lives of those who experience it daily.

The first picture entitled 'Pelvic Pain or Whole-body?' showed the disparity found in research in how the disease is presented. Much of the literature written about endometriosis refers to the presence of pelvic pain. Studies cited included Taylor et al, 2021; Sinaii et al, 2002; and Kvaskoff et al 2015, all who identified links between endometriosis and higher risk of other diseases. They also showed endometriosis as a whole-body disease. This is in contrast to many definitions including the NHS and Oxford dictionary which depict endometriosis as a condition resulting from the appearance of endometrial tissue outside the uterus causing pelvic pain.

The second picture illustrated Djalali's 2007 endometriosis study, that identified endometriosis as a chronic inflammatory disease. Inflammation occurs due to the immune system malfunctioning and attacking its own tissues, releasing cytokines and subsequently affecting the central nervous system. Work by Wu and Ho, 2003 and Mira et al, 2018 showed how the characteristics of the disease illustrate that inflammation is present and that persistent symptoms contribute to wider impacts on quality of life, as sufferers may feel there is no relief from symptoms even after treatment has been received.

Picture three shows impacts of endometriosis on mental health. Specifically, a quote by Zarbo (2018) that says endometriosis is a disabling and long-term medical condition affecting quality of life and mental health. The picture also illustrates research findings from the 2020 All Party Parliamentary Group on endometriosis which released an inquiry report documenting the experience of over 10,000 endometriosis sufferers, 95% of whom said that endometriosis had impacted their well-being in a negative manner. There are many studies that recognise the strong correlation between coping with endometriosis pain and levels of depression and anxiety, including a study by Wang et al 2021, which suggests that endometriosis can disturb mental health specifically depression and anxiety.

Picture four 'The Everyday Task' can be considered the most relevant in addressing the research question of the impact of endometriosis on a patient's quality of life. Patients with endometriosis frequently experience broader symptoms as documented in studies by Ferrero et al, 2008; Ramin-Wright et al, 2018; DiBenedetti et al, 2020 and a further study by Álvarez-Salvago et al 2020, with the results indicating women with endometriosis show signs of deteriorated health-related fitness, poor sleep quality, body balance and functional capacity. Symptoms also include fatigue, headaches, insomnia, brain fog, severe migraines and difficulty concentrating. This can have a major impact on the ability to work, attend education or simply join in day-to-day activities.

Picture five illustrates medical bias. Despite endometriosis producing recognised quality of life impacts, diagnosis times have remained unchanged over the last decade at an average of 8 years. Many endometriosis sufferers have made multiple trips to the GP and emergency hospital visits with Wren and Mercer 2022 reporting that clinicians repeatedly normalise and dismiss patient symptoms. The APPG on endometriosis highlighted a major cause of stress and psychological damage was patient dismissal by medical professionals. This picture illustrates the delays in diagnosis times, potentially impacted by this bias and how patients may also feel ashamed, guilty or disbelieved.

The final picture represents Masking. Munir et al 2005 suggest that masking is where patients who have been living with long-term pain, learn to hide their feelings and symptoms due to potential rejection, discrimination, loss of social support and loss of employment. The APPG evidenced this further by noting that over a third of survey participants were concerned about losing their job or having reduced income. Zarbo 2018 suggests that women with endometriosis have been found as more likely to repress emotions. A study by Ballard et al, 2006, found that patients subsequently learnt to live with pain, to ignore it or habitually blank out trauma or feelings, preferring to accommodate rather than disclose their pain. This can significantly impact their quality of life.

**Ren Hodges speaks** ' I created this er piece of art for Martyna's exhibition 'Do You See Me Now?'. It's an attempt to illustrate endometriosis which is a sort of invisible disease, so the lesions that would otherwise be erm intertwined with internal organs have been placed on the outside of the skin. So to start with I was given Martyna's research and some patient statements and I used this as a starting place and my own experiences to create this piece.

**Narrator:** Visitors were asked to complete an online survey question before leaving the exhibition. The question was 'What will you take away with you from today's exhibition?' These were some of the responses.

And so in answer to the research question 'To what extent does Endometriosis, as a whole-body disease, impact upon the quality of life for sufferers in the UK?' research findings indicate the disease impacts not only physical health but has wider implications for mental health and well-being of patients, and can impact work, education and the ability to carry out day-to-day activities. It is also suggested that more research is needed to identify the cause of the disease and to better understand it's full extent.