Northern Ireland
Public Services
Ombudsman

Investigation Report

Investigation of a complaint against the South Eastern Health and Social Care Trust

NIPSO Reference: 19081

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The Role of the Ombudsman

The Northern Ireland Public Services Ombudsman (NIPSO) provides a free, independent and impartial service for investigating complaints about public service providers in Northern Ireland.

The role of the Ombudsman is set out in the Public Services Ombudsman Act (Northern Ireland) 2016 (the 2016 Act). The Ombudsman can normally only accept a complaint after the complaints process of the public service provider has been exhausted.

The Ombudsman may investigate complaints about maladministration on the part of listed authorities, and on the merits of a decision taken by health and social care bodies, general health care providers and independent providers of health and social care. The purpose of an investigation is to ascertain if the matters alleged in the complaint properly warrant investigation and are in substance true.

Maladministration is not defined in the legislation, but is generally taken to include decisions made following improper consideration, action or inaction; delay; failure to follow procedures or the law; misleading or inaccurate statements; bias; or inadequate record keeping.

The Ombudsman must also consider whether maladministration has resulted in an injustice. Injustice is also not defined in legislation but can include upset, inconvenience, or frustration. A remedy may be recommended where injustice is found as a consequence of the failings identified in a report.

Reporting in the Public Interest

This report is published pursuant to section 44 of the 2016 Act which allows the Ombudsman to publish an investigation report when it is in the public interest to do so.

The Ombudsman has taken into account the interests of the person aggrieved and other persons prior to publishing this report.

TABLE OF CONTENTS

Page

SUMMARY

This complaint is about the actions of the South Eastern Health and Social Care Trust (the Trust). The patient attended a consultant gynaecologist in the Ulster Hospital and was placed on an urgent waiting list for a laparoscopic excision[1] of Stage IV endometriosis[2] in September 2016. She was informed in November 2017 that a cap[3] was in place and that she would not be undergoing surgery in the '*foreseeable future'*. The patient remained on the waiting list until she underwent surgery in September 2020.

The patient said that her condition was allowed to progress while waiting for treatment. She also said that the Trust did not monitor her condition during this time, and raised concerns about the Trust's failure to undertake relevant MRI scans. The patient said that the Trust would not refer her to a specialist mainland United Kingdom (UK) centre for treatment, and did not inform her that she could have the procedure undertaken in another Trust area within Northern Ireland.

The investigation examined the details of the complaint, the Trust's response, its policies, and relevant NICE guidelines. Independent professional advisors were asked for an opinion on the patient's treatment. The advisors agreed that the patient's wait for surgery was unacceptable. They considered that while the Trust appropriately monitored the patient's condition, including undertaking relevant MRI scans, the patient or her general practitioner rather than the Trust initiated the review appointments. Furthermore, the advisors identified that the Trust did not provide the patient with appropriate medication to minimise the progression of her condition. I accepted this advice. The investigation also identified that the Trust was not required to refer the patient to a specialist centre within mainland UK to have the surgery. The complaint was partly upheld.

[1] Surgery in which doctors remove growths and scar tissue or destroy them using intense heat. The endometriosis is treated without harming the healthy tissue of the uterus around the abnormal growths.
[2] A disorder in which tissue similar to that which normally lines the inside of the uterus — the endometrium — grows outside the uterus. Stage IV is the most severe and involves deep implants on the pelvic lining and ovaries. There may also be lesions on the fallopian tubes and bowel.
[3] Treatment for persons on the waiting list is stopped for a period.

THE COMPLAINT

1. I received a complaint about the care and treatment the South Eastern Health and Social Care Trust (the Trust) provided to the patient.

Background

2. The patient said that she attended the Ulster Hospital for an MRI[4] [magnetic resonance imaging] in May 2016. The MRI showed a small left ovarian endometrioma[5] measuring 2.4cm in diameter. It also showed significant thickening extending to the adjacent rectosigmoid colon[6]. The patient was diagnosed with Stage IV endometriosis with involvement of sigmoid colon[7] in August 2016. In September 2016 she was placed on her consultant gynaecologist's urgent waiting list for a laparoscopic excision of endometriosis. The patient was informed in November 2017 that a cap was in place and that she would not be undergoing surgery in the '*foreseeable future'*.

3. The patient said that a second MRI was performed on her in December 2018. She was informed that the ovarian cyst increased in size to 8.2cm in diameter. At the time of raising her complaint, the patient was number six on the list. She later moved down the list to number nine. Her surgery was undertaken in September 2020.

Information relating to the treatment of endometriosis within Northern Ireland

The Health and Social Care Board (HSCB)

4. The HSCB explained that '*the enhancement of existing endometriosis services was raised within the NI [Northern Ireland] Assembly on 17 June 2013, highlighting the physical and psychological effects the condition has on women. A number of issues were raised including difficulties in receiving a diagnosis, pain management and the range of treatment options available. There was a consensus that greater public awareness of the condition was required and that existing patient pathways should be reviewed and enhanced*'.

[4] A technique used in radiology to form pictures of the anatomy and the physiological processes of the body.
[5] A type of cyst formed when endometrial tissue grows in the ovaries.
[6] The rectosigmoid junction is between the sigmoid colon and rectum.
[7] The part of the large intestine that is closest to the rectum and anus.

5. The HSCB further explained that '*a business case for a regional endometriosis centre within the Belfast Trust was developed however this was unable to be progressed due to the wide range of competing financial pressures. Notwithstanding the current financial context, the HSCB has been able to progress the commissioning of a clinical nurse specialist within the Trust. It is accepted that while services have developed, specifically in Belfast and Western Trust areas, the pace and scale of the change required has not been achieved. Further work is now required to develop plans to further enhance existing services within available resources'*.

6. The HSCB explained that '*generally, endometriosis services across Northern Ireland are provided on an ad-hoc basis as a sub-speciality within gynaecology services. There are no specific endometriosis services within the Northern and Southern areas and there is a limited service within the South Eastern Trust. Patients in these areas are usually referred to services within the Belfast and Western Trust. While these services are more developed, further work is required to improve the patient pathway and experience'*.

Treatment the South Eastern Health and Social Care Trust provides

7. The Trust explained that there are three categories of surgical waiting lists: red flag, urgent and routine. Those patients on the urgent and routine lists are initially placed in chronological order. However, a patient can move up or down the list if their condition changes. This can affect the position of other patients on the list. The Trust explained that nine surgical sessions (morning and afternoon) are allocated to the gynaecological team per week. These sessions run Monday to Friday. However, emergency surgeries can occur at the weekend.

8. The Trust explained that there are patients, such as the patient, who require other surgical specialties (as well as the consultant gynaecologist). It also explained that when the patient reaches the top of the list, the Trust considers the availability of the required surgeon. The Trust explained that patients on the urgent waiting list have undergone surgery since 2016. However, these patients may not require the input of a surgeon from another specialist area. The Trust

explained that patients on the list may require surgery more urgently. In these cases, patients can move up the waiting list.

9. The Trust explained that it has experienced increased pressure for availability of inpatient beds over recent years. It also explained that a way to manage these pressures was to cap the elective lists. The Trust explained that the decision to cap the lists is reviewed on a weekly basis. It further explained that a cap may be lifted in spring or early summer as the winter pressures subside. However, this has not been the case since the closure of an emergency department in the Belfast Health and Social Care Trust area in 2013.

Issue of complaint

10. The issue of complaint accepted for investigation was:

Issue 1: Whether the care and treatment of the patient, in relation to her endometriosis, between September 2016 and December 2018 was reasonable, appropriate and in accordance with relevant standards.

INVESTIGATION METHODOLOGY

11. In order to investigate the complaint, the Investigating Officer obtained from the Trust all relevant documentation together with the Trust's comments on the issues the patient raised. This documentation included information relating to how the Trust handled the complaint.

Independent Professional Advice Sought

After further consideration of the issues, I obtained independent professional advice froma consultant gynaecologist and accredited endometriosis surgeon working in an accredited centre (G IPA).

12. Further to the patient's and the Trust's responses to a draft copy of this report, I obtained further independent professional advice from a consultant gynaecologist for over 20 years (G IPA (2)).

13. The information and advice that informed the findings and conclusions are included within the body of the report and its appendices. The IPAs provided me with 'advice'; however how I weighed this advice, within the context of this particular complaint, is a matter for my discretion.

Relevant Standards

14. In order to investigate complaints, I must establish a clear understanding of the standards, both of general application and those which are specific to the circumstances of the case. I also make reference to relevant regulatory, professional and statutory guidance.

15. The general standards are the Ombudsman's Principles[8]:
    - The Principles of Good Administration
    - The Principles of Good Complaint Handling
    - The Public Services Ombudsmen Principles for Remedy

16. The specific standards are those which applied at the time the events occurred, and which governed the exercise of the administrative functions and professional judgement of the Trust staff whose actions are the subject of this complaint.

17. The specific standards relevant to this complaint are:
    - The National Institute for Health and Care Excellence's (NICE) guideline on Endometriosis: diagnosis and management, September 2017 (NICE NG73);
    - The Department of Health, Social Services, and Public Safety's Integrated Elective Access Protocol (DHSSPS), 30 April 2008 (the DHSSPS Protocol);
    - The Health and Social Care Board's (HSCB) Arrangements for the Consideration of Request for Care and/or Treatment on Behalf of Individual Patients, not dated (the HSCB Arrangements);
    - The South Eastern Health and Social Care Trust's (the Trust) Policy for the Management of Private Practice, May 2011 (the Trust's Policy for the

[8] These principles were established through the collective experience of the public services ombudsmen affiliated to the Ombudsman Association.

Management of Private Practice); and

- The International Covenant on economic and social and cultural rights (ICECSR), ratified by the UK in 1976 (the ICECSR).

18. I also referred to the following briefing/research papers:
    - Northern Ireland Assembly Research and Information Service Research Paper 02/20 'Waiting Lists and Waiting Times for Elective Care in Northern Ireland: Taking Stock', 31 January 2020 (The Assembly research paper);
    - The Northern Ireland Human Right's Commission (NIHRC) Human Rights Inquiry: Emergency Health Care, May 2015 (the NIHRC Inquiry); and
    - Northern Ireland Ombudsman Human Rights Manual, 2015 (the NIPSO Human Rights Manual).

    Relevant extracts are enclosed at Appendix three to this report.

19. I did not include all of the information obtained in the course of the investigation in this report. However, I am satisfied that I took into account everything I considered to be relevant and important in reaching my findings.

20. A draft copy of this report was shared with the patient and the Trust for comment on factual accuracy, and the reasonableness of the findings and recommendations.

INVESTIGATION

Issue 1: Whether the care and treatment of the patient in relation to her endometriosis between September 2016 and December 2018 was reasonable, appropriate and in accordance with relevant standards.

Detail of Complaint

21. I received a complaint about the care and treatment the patient received from the Trust. She complained about the delay in accessing the treatment she requires for Stage IV endometriosis (diagnosed in May 2016). The patient said that her condition was allowed to progress due to not receiving the necessary

treatment. She also said that the Trust did not monitor her condition.

22. The patient raised concerns that the Trust reclassified an urgent MRI her GP requested for her in August 2018 as routine. She said that further MRI imaging may have showed a worsening of her condition, and could have potentially moved her up the waiting list. She explained that she enquired with the Consultant Obstetrician and Gynaecologist (the Consultant), regarding having the MRI privately. However, he advised her that his colleagues were unable to assess private MRI images. The patient explained that since submitting her complaint, she attended an MRI on 23 December 2018.

23. The patient also raised concerns that the Trust would not refer her to a specialist mainland UK centre for treatment. She explained that it was unlikely she would undergo the surgery in Northern Ireland within the '*near future'* due to the length of the waiting lists and the cap in place. She also explained that the Trust did not inform her that she could have the procedure in another Trust area within Northern Ireland. The patient further explained that she did not have the option of private treatment within Northern Ireland as the surgery required the availability of a bed in intensive care.

24. The patient raised questions with the Trust. She queried what assessment the Trust made in respect of the '*risk of deterioration and disease progression of her condition'*, and '*complications arising from the increasing size of ovarian endometria'* given the period of time that she was on the waiting list. The patient further questioned what plans the Trust had in place to manage and monitor her while she awaited her surgery. She also queried what plans the Trust have to introduce a '*specialist service for those with suspected or confirmed endometriosis in Northern Ireland'*, and whether the Trust engaged with other Trusts with a view to introducing such a service.

Evidence Considered

Legislation/Policies/Guidance

25. I considered extracts from the following guidance:

i. NICE NG73;
ii. The DHSSPS Protocol;
iii. The HSCB Arrangements;
iv. The Trust's Policy for the Management of Private Practice;
v. The ICECSR;
vi. The Assembly research paper;
vii. The NIHRC Inquiry; and
viii. The NIPSO Human Rights Manual.

The Trust's response to investigation enquiries

26. The Trust explained that '*all patients who are referred to the Trust Gynaecology team are triaged by a consultant'*. It further explained that '*each of these lists [red flag, urgent and routine] are reviewed weekly by the Clinical Director and patients are appointed for surgery based on their categorisation and bed availability the following week'*. The Trust said that the '*urgent waiting list target is 12 weeks'*. It explained that '*as of 15 July 2019, there are currently 112 women waiting on [the Consultant's] urgent waiting list…[the patient] is sixth on…[the] list'*. At the time of providing its response, the Trust explained, '*regrettably we are unable to give a date for surgery at this time...[the] waiting list is reviewed weekly and is reducing, albeit slower than [the patient] and the team would want'*.

27. The Trust apologised to the patient for the delays experienced in accessing the required treatment. It explained that the Trust '*continues to experience increasing demand for services. Also there is limited inpatient capacity due to ongoing unscheduled care pressures. As a result, it has been necessary to reduce the number of patients admitted to hospital every week for elective surgery. Unfortunately, this includes [the patient] and other women'*. The Trust added, '*unfortunately, this has created unacceptable waiting lists within the Trust for inpatient Elective Surgery'*.

28. The Trust explained that '*there are monthly Benign Gynaecology MDT meetings to discuss complex cases with links between gynaecology, radiology, colorectal surgery, specialist pain services and gynaecology surgery'*. It also explained that '*the Trust is engaged with the HSCB and the other four Trusts in*

the Gynaecology Regional Outpatient Reform[9] *and is reviewing all gynaecology services including an Endometriosis NI [Northern Ireland] pathway and service'*.

29. The patient referred to the NICE guidelines relating to delays in treatment. In response to this element of the complaint, the Trust explained that it '*accepts that delays in treatment result in negative impacts and disease progression. [The patient] continues to be reviewed while waiting for surgery'*.

30. In relation to the MRI requested for the patient, the Trust explained that '*we wish to assure [the patient] that her MRI on 23 December 2018 did not cause a delay in her surgery'*. The Trust further explained that a '*repeat MRI is not required for surgery as we already know the endometriosis involves bowel and have counselled [the patient] accordingly. The actual extent of the disease will not be fully known until surgery'*.

31. The Trust explained that '*it is not considered best practice for an MRI to be undertaken privately and then surgery to be undertaken in the Trust. The Trust has a monthly Benign Gynaecology Multidisciplinary Team (MDT) meeting with radiology and other colleagues. The MDT discusses women with complex gynaecology conditions, such as [the patient], and together agrees the most effective treatment. The radiology team do not have access to MRI or other investigations undertaken privately, and even if they were available, they are often not undertaken in the specific manner required by the team. As a result, discussion of these cases at the meeting could not take place'*.

32. In relation to the complaint that the patient's condition progressed due to treatment nor monitoring being undertaken, the Trust explained that '*[the patient] has been regularly reviewed by a consultant gynaecologist over the past three years'.* The Trust provided a chronology of the reviews undertaken during this period:

July 2016	The patient underwent a sigmoidoscopy and a decision was made for surgery.
September 2016	The patient was placed on the joint waiting list for the Consultant and the colorectal surgeon.

[9] A process to review and reform the treatment of gynaecological health concerns in Northern Ireland.

26 June 2017	Reviewed by the Consultant.
19 February 2018	Reviewed by the Consultant.
17 September 2018	Reviewed by the Consultant.
18 January 2019	The patient's case was discussed at the Trust's Benign Gynaecology MDT meeting.

33. In relation to what assessments of the progression of the disease, and of the complications arising from the increasing size of ovarian endometria, have been undertaken, the Trust explained that an '*assessment of [the patient's] disease progression is undertaken at each of these appointments / discussions. At her next review appointment on 25 February 2019, [the Consultant] will discuss the findings of the Trust's Benign Gynaecology MDT meeting on 18 January 2019 and treatment while waiting on surgery'*.

34. In relation to the complaint that the Trust did not refer the patient to a specialist UK centre for treatment, the Trust explained that *'extra contractual referrals from the HSCB are for services not available within Northern Ireland. The treatment required by [the patient] is available in Northern Ireland, albeit the wait is protracted due to pressures highlighted above'*.

35. In relation to plans that the Trust may have to introduce a specialist service for patients experiencing endometriosis, the Trust explained that '*all Trust consultant gynaecologists diagnose endometriosis, usually by a combination of history, examination, pelvic ultrasound scan, MRI scan and/or diagnostic laparoscopy. Surgical treatment for more advanced disease is referred to [the Consultant], who has a special interest in minimal access surgery including treatment of advanced endometriosis. [The Consultant] has operating sessions in the Ulster Hospital with [the colorectal surgeon], who has an interest in the treatment of advanced endometriosis. Together they perform advanced laparoscopic resection of disease including laparoscopic bowel resections'*.

36. The Trust explained that it '*continues to work with the Health and Social Care Board (HSCB), as Commissioner, in an attempt to create the additional capacity required to enable us to reduce the current waiting time. The*

Department of Health and HSCB are aware of these pressures and are updated on progress regularly'. It further explained that '*within the South Eastern Trust, operating time in theatres is managed through the allocation of theatre sessions or lists. Each theatre runs morning and afternoon sessions daily, primarily on a Monday to Friday basis…the length of sessions can vary, based on what has been commissioned by the Health and Social Care Board*'. The Trust explained that there is '*one Consultant Gynaecologist who is able to perform this procedure…there is one Consultant Colorectal Surgeon who has a special interest in these types of cases'*.

37. The Trust was asked how it balances theatre times with the needs of the patient and other specialist disciplines. It explained that '*each specialist discipline is allocated a fixed number of theatre sessions per week within the Trust. Again this is dependent on what has been commissioned by the Health and Social Care Board. Each session is populated with patients based either on their clinical needs / priority or in chronological order for elective cases / procedures'*.

38. The Trust was asked how it was working to create additional capacity to reduce current waiting list times specific to the gynaecological surgical waiting list. It explained that '*the Department of Health and HSC Board are aware of these pressures and are updated on progress regularly. The main issue affecting the Ulster Hospital is the increasing demand for inpatient beds for unscheduled care, which has reduced capacity for elective surgery and increased the waiting lists on all specialities, including Gynaecology*'. It further explained that '*gynaecology emergency admissions account for half of all emergency admissions to the ward, and the other half from different specialities including early pregnancy loss, general surgery and medicine (largest group). Unlike an elective surgical patient, an emergency admission can be in longer, especially medical elderly patients, therefore decreasing the ability of the ward to admitted elective cases'*.

Clinical Records

39. The patient's clinical records were carefully considered. A chronology of her care and treatment was prepared and is enclosed at Appendix five to this

report.

40. The clinical records document that the Consultant referred the patient to a Colorectal Surgeon in May 2016. She was placed on the urgent waiting list for a laparoscopic excision of endometriosis following an appointment with the Consultant in September 2016.

41. The clinical records document that the patient attended her GP in January 2018 reporting increased pain and swelling. The GP submitted a 'red flag' referral to the Ulster Hospital and the patient was reviewed on 12 February 2018. The records document that the Consultant was asked to consider bringing the planned surgery forward. They further document that the Consultant advised that the patient was to remain on the urgent waiting list.

42. The clinical records document that the patient's GP wrote to the Ulster Hospital on 1 May 2018 to request an earlier review and a repeat MRI. The Consultant informed the GP on 31 May 2018 that further to her request, an outpatient appointment was arranged for the patient for September 2018.

43. The outpatient clinical records document the notes of a phone call the patient made to the Consultant's office on 19 November 2018. The note documents that the patient enquired if she could proceed with an MRI (undertaken privately) with '*reassurance can be interpreted here'*. The note further documents, '*not possible. Can have MRI but not interpreted in NHS'*.

44. The clinical records document that the patient attended for an MRI on 23 December 2018. The report documents that the ovarian cyst increased in size from 2.4cm (measurement taken in May 2016) to 8.2cm in diameter.

Additional information considered

45. The Investigating Officer sought the views of the HSCB regarding commissioning for the South Eastern Trust area. It explained that referrals are managed through weekly outpatient and theatre sessions for gynaecology. It further explained that the Trust has a wider multi-disciplinary team including a radiologist, colorectal surgeon and gynaecologists with links to a specialist pain team and gynaecology physiotherapist. This team meet on a monthly basis to

discuss complex cases, including those related to endometriosis. The HSCB explained that surgical treatment is available within the Trust, including advanced laparoscopic resection.

46. The HSCB explained the Trust place a cap on waiting lists to manage the additional pressures experienced during the winter period. However, as the pressures occur year round, the cap remains in place. It further explained that it commissions a number of theatre sessions per week for the Trust to undertake. It is the Trust's responsibility to allocate these procedures within the specialist area. The area encompasses a wide range of surgical procedures including those related to endometriosis. The HSCB explained that the Trust was expected to undertake 2243 obstetrics and gynaecology inpatient and day cases for the period 1 April 2019 to 31 January 2020. The HSCB explained that for the period specified, the Trust undertook 1379 inpatient and day cases. This was a variance of -39%. It also explained that this variance is likely affected by the cap in place and the number of emergency procedures undertaken.

47. The HSCB explained that there are two accredited centres for the treatment of endometriosis within Northern Ireland, based in the Western and Belfast Trust areas. It explained that Trusts can refer those patients diagnosed with Stage III and Stage IV endometriosis to other Trust areas to undergo the required surgery. The HSCB explained that this may minimise the delay currently experienced. As part of investigation enquiries, the Investigating Officer asked the HSCB to provide evidence that it made Trusts aware that it could refer patients to other Trust areas for treatment. However, it was unable to provide this supporting evidence.

Relevant Independent Professional Advice

48. As part of investigation enquiries, the advice of a consultant gynaecologist and endometriosis surgeon was obtained (G IPA).

49. The G IPA advised that '*[the patient] was diagnosed with endometriosis in Jan[uary] 2015. She had a left ovarian cyst measuring 7cms which was treated surgically in May 2015, when a diagnosis of severe endometriosis was made. She was reviewed in July 2015 and started on GnRHa [gonadotropin-releasing*

hormone] suppression therapy[10]*– the course of treatment was completed in Dec[ember] 2015. On 19 May 2016, she underwent a MRI pelvis, which showed a 24mm left ovarian cyst and rectosigmoid scarring. She was added to the waiting list for surgery in Sep[tember] 2016. USS [ultrasound scanning] in clinic on 26 June 2017 showed a 4cm cyst. The cyst size was 75mm as measured by USS in Jan[uary] and Sep[tember] 2018 and 82mm as per MRI 23 Dec[ember] 2018. The MRI noted that apart from an increase in size from 24 to 82mm, there was no significant change in other findings including rectovaginal*[11] *and right adnexa*[12] *between the two examinations in 2016 and 2018'*.

50. The G IPA also advised that '*endometriosis is a hormone sensitive condition, and therefore in the absence of any interim medical or surgical therapies, or natural events such as pregnancy/breast feeding, and menopause, it continues to progress. The subjective means of monitoring progress is by assessing change/progression of symptoms, whereas the objective way of monitoring progress is by assessing change/progression in imaging and surgical findings. It is recorded in the notes that the [the patient] was increasingly symptomatic since May 2016 and that her cyst increased gradually in size over a period of time. Therefore, in all likelihood her endometriosis progressed in severity, however, because the initial staging was already graded as severe, it is difficult to objectively define further increments in severity. The MRI did not suggest any change in either the spread of the disease or its severity other than an increase in size of cyst, and, on balance, the further increment in severity due to the delay is minimal'*.

51. The G IPA was asked what impact this had on the patient. He advised that '*the delay in surgical treatment has prolonged her pain and suffering. The delay may also reduce her chances of conception, and progressively impact on bowel and bladder function over time'*. The G IPA was also asked if there was any way that the impact on the patient could have been minimised. He referred to sections 1.8.5 and 1.8.6 of NICE NG73 and advised that '*she could have been*

[10] Treatment with a GnRH agonist leads to a decrease of oestrogen to the levels that women have after menopause.
[11] The connection between the lower portion of the rectum and the vagina.
[12] The ovaries, Fallopian tubes, and the ligaments that hold the uterus in place.

offered medical therapies for example OCP (oral contraceptive pill), LNG-IUS[13] [levonorgestrel-releasing intrauterine system], or even recourse to GnRHa with HRT[14] [hormone replacement therapy] addback. These will/would reduce rates of progression and may induce a degree of regression in both symptoms and size/severity of endometriosis lesions'.

52. The G IPA provided a chronology of the medical reviews the patient attended regarding her condition. This chronology is enclosed in Appendix five to this report. The G IPA referred to section 1.7 of NICE NG73 and advised that '*the reviews were appropriate. She could have been offered medical therapies as outlined earlier while awaiting surgery'*.

53. The G IPA was asked if he considered that the patient ought to have had an MRI undertaken earlier than December 2018. He advised that '*she had regular follow-up visits and USS imaging. MRI was not indicated'*. In relation to the possibility of the patient attending an MRI privately (not through the National Health Service), the G IPA advised that '*[the patient] phoned on 19 Nov[ember] enquiring about [the] possibility of [a] MRI being done privately but being interpreted locally. The Trust informed her that whilst she can have the MRI done privately, the Trust would not be in position to re-interpret the results'*. He further advised that '*it is…common practice amongst radiologists/radiology departments not to re-interpret results/reports from an external provider, unless…sought as [a] second opinion or providing medicolegal [medical legal] advice'*. The G IPA was asked if having an MRI undertaken privately would have benefitted the patient. He advised that '*there was no indication for MRI except prior to surgery. Since the date for surgery was not yet finalised, there was no need to expedite MRI'*.

54. The G IPA advised that '*the follow-up and monitoring was appropriate, although, on further review of the notes it does appear that some of the monitoring visits were triggered by GP referrals rather than routine. Medical/hormonal therapies were not offered w.e.f. [with effect from] 2016*

[13] A form of contraception. It has also been used in combination with oestrogen for hormone replacement therapy and as an alternative to hysterectomy.
[14] Used to help balance oestrogen and progesterone in women around the time of menopause.

whilst awaiting surgery. The delay in surgery is regrettable and the Trust has apologised for this, but, by the looks of it not avoidable given the level of service provision. NICE [NG73] does not stipulate timescales to surgery. Nevertheless, awaiting more than 12 months for appropriate treatment should be deemed unacceptable, and, the surplus demand should be outsourced to any qualified provider including the private sector…this is good medical practice as otherwise, in absence of effective medical and surgical therapies, her endometriosis will progress'.

55. The G IPA was asked to identify any learnings or service improvements in relation to the complaint. He advised that the Trust ought to '*improve waiting times for surgery; outsource long-waiters to any qualified provider; [and] offer medical/hormonal therapies whilst awaiting surgery'*.

The patient's response to a draft copy of this report

56. In relation to the Trust's monitoring of the patient's condition while she was awaiting surgery, the patient said that either she or her GP initiated the review appointments undertaken.

The Trust's response to a draft copy of this report

57. The Trust explained that it did not initiate any of the review appointments undertaken for the patient between September 2016 and February 2019. It said that this was because the patient '*had a confirmed diagnosis and was planned for urgent surgery'*. The Trust further explained that upon reflection, and in accordance with NICE NG73, it '*will offer outpatient reviews for all women with endometriosis. The frequency of the reviews will be based on the patient's clinical condition'*.

58. The Trust explained that it is '*unaware of any such system indicated by the HSCB, which allows Trusts to refer to other Trusts any patients diagnosed with Stage 3 and Stage 4 endometriosis to undergo surgery to prevent delay in treatment'*. It also said that cases, such as the patient's, could not be '*referred to the private sector due to the requirement of an Intensive Care facility on site in case of complications from such surgery required'*.

59. In relation to treatment while she awaited surgery, the Trust explained that it offered the patient '*Gonadotrophin reducing hormone agonists (GnRH) and hormone replacement therapy (HRT) in July 2015, which she took. [The patient] stated she had unpleasant side effects with this treatment and decided she did not want to take it'*. It also explained that in November 2015 it discussed Progesterone treatment with the patient '*but it is unclear from the medical records whether she took this form of treatment or not'*. The Trust said that in September 2016, it discussed the Mirena coil with the patient and she '*opted to have this inserted at the time of surgery'*.

60. In relation to the MRI request, the Trust explained that the patient's GP requested an urgent MRI. However, '*following a review by a Consultant Radiologist, and based on the clinical information provided, it was re-classed as 'routine"*. It further explained that as the patient was on the urgent list for surgery, '*there was not going to be any change in priority as a result of the MRI'*, and '*disease progression, as assessed by an MRI, was not going to change the management plan'*.

Further relevant IPA advice

61. The G IPA (2) advised that '*the advice from NG73 is deliberately vague as some teams would not organise routine follow-up and some would not. I do not feel that the Trust needs to provide evidence that they considered it. It appears they made a decision not to monitor. However, the patient had already had a further referral via the GP and had also been seen at her request, consequently she was reviewed on a regular basis. The wording of the document gives the Trust latitude to not review and as such they are acting within the wording of the guideline'*.

62. He further advised that '*the fact that the patient was not admitted for her procedure for >4years should have instigated further review. Had she not been reviewed within this period I would have regarded this as inappropriate. It would seem reasonable for patients on a long waiting list (>1year) that an automatic review should take place even as a common courtesy, to explain the situation and to ensure there are no new/deteriorating symptoms'*.

63. The G IPA (2) advised that the records evidence that the Trust did not prescribe any medication for the patient after she was added to the urgent waiting list in September 2016 and before she raised her complaint. He advised that the patient '*was offered…GnRH agonist treatment, she declined this as she felt her previous trial of GnRH was unsuccessful and did not stop her periods. It does not appear that alternative therapies were offered at this time'*. The G IPA (2) was asked if there was any medication that the Trust could have offered to the patient. He advised that '*continuous progesterone therapy or continuous combined oral contraceptive pill or Levonorgestrel (progesterone) containing IUS (Mirena IUS) could have been offered. These are sometimes less effective than GnRH but nonetheless can be effective in some patients'*.

64. The G IPA (2) referred to the Trust's comments regarding the insertion of a Mirena coil. He advised that '*the implication from the agreement to insert the Mirena IUS at the time of surgery is that the surgery would be in the relatively near future as there is no benefit whatsoever in delaying the insertion for several months to years'*.

65. In relation to the impact this likely had on the patient, the G IPA (2) advised that '*she would suffer from continuing symptoms which were likely to worsen as the disease progressed. Any treatment aimed at stopping her normal menstrual cycle was likely to improve her symptoms and possibly slow disease progression when compared to the effect of no treatment at all'*.

66. In relation to the patient's MRI, the G IPA (2) advised that '*an MRI scan is not mandatory in the follow up of endometriosis (NG73). The [patient] had already been diagnosed with stage 4 endometriosis and as such further imaging is unlikely to have changed the management pathway and certainly would not have changed the clinical staging'*. He further advised that '*given that the [patient] had already been diagnosed with stage 4 endometriosis, the only important imaging is the pre-operative MRI. As there was no operation date arranged, it was reasonable to defer arranging a scan until a definitive operation date was decided'*.

67. The G IPA (2) advised that '*it was appropriate to request the MRI as routine. There was no evidence that here had been a significant change in the patient's symptoms which would indicate that the MRI should have been requested as urgent'*.

Analysis and Findings

Delay in receiving surgery

68. The patient raised concerns about the delay in receiving the surgery she required to treat her Stage IV endometriosis. She said that the disease was allowed to progress due to not receiving the necessary treatment. The patient also said that the Trust did not appropriately monitor her condition. I note that the patient was added to the urgent waiting list for surgery in September 2016 and the surgery was undertaken in September 2020. The Trust explained that the urgent waiting list target is 12 weeks. However, the patient waited four years for the required surgery. I consider this waiting time significant and unacceptable.

69. I note that the HSCB commissioned the Trust to undertake 2243 obstetrics and gynaecology inpatient and day cases for the period 1 April 2019 to 31 January 2020. However, I note that the Trust undertook just 1379 cases in that period. I note that the Trust explained that it '*continues to experience increasing demand for services. Also there is limited inpatient capacity due to ongoing unscheduled care pressures. As a result, it has been necessary to reduce the number of patients admitted to hospital every week for elective surgery'.*

70. I acknowledge the increased pressures placed on the Trust which have led to significant delays in undertaking elective procedures. However, I accept the G IPA's advice that '*awaiting more than 12 months for appropriate treatment should be deemed unacceptable, and, the surplus demand should be outsourced to any qualified provider including the private sector…this is good medical practice as otherwise, in absence of effective medical and surgical therapies, her endometriosis will progress'*.

71. I note that there is an option for the Trust to refer patients to other Trust areas within Northern Ireland for treatment. However, I note the patient's view that

this was never discussed with her. In its response to a draft copy of this report, the Trust explained that it was unaware it could refer patients to other Trust areas for this treatment. I note that the HSCB was unable to provide evidence that it made the Trust aware of this arrangement. In the absence of this evidence, I cannot conclude that the Trust was aware that it could offer the patient treatment elsewhere. Therefore, I also cannot conclude that the Trust failed to utilise the full resources available to ensure that the patient was provided with the surgery required to prevent further progression of the patient's condition.

72. The patient also raised concerns about the Trust's monitoring of her condition during the time she spent on the urgent waiting list. I note that NICE NG73 recommends that Trusts **consider** [my emphasis] outpatient monitoring for women with endometriosis involving the bowel. I also note the list of consultations the patient attended since September 2016. I accept the G IPA's advice that '*the follow-up and monitoring was appropriate'*.

73. While I consider that the monitoring of the patient's condition was undertaken in accordance with NICE NG73, the Trust accepted that it was the patient or her GP that initiated the outpatient appointments. I note that NICE NG73 does not place an obligation on Trusts to review patients. However, I accept the G IPA (2)'s advice that due to the length of the delay in the surgery, '*automatic review should take place even as a common courtesy, to explain the situation and to ensure there are no new/deteriorating symptoms*'. I find it concerning that within that four year period, the Trust failed to invite the patient to an outpatient appointment without being prompted to do so. I consider this a failure in the patient's care and treatment. I note that the Trust said that it will now offer outpatient reviews to patients dependent on their individual symptoms. I welcome this learning.

74. I considered the treatment offered to the patient during the time she spent on the waiting list. I note NICE NG73 states that women with confirmed endometriosis ought to be offered hormonal treatment. The Trust explained that the patient was treated with GnRH in 2015. However, I note that this was discontinued shortly afterwards. The Trust also explained that the patient opted

to have the Mirena coil inserted during her surgery. However, I note the G IPA (2)'s advice that this would not have had any benefit due to the delay in her surgery. I note both IPAs' advice that the Trust ought to have offered the patient additional treatment while waiting on her surgery. However, based on the records available to me, I am satisfied that appropriate treatment was not discussed nor offered to the patient after she was added to the waiting list in September 2016 and before she raised her complaint. I am satisfied that this represents a failure in the care and treatment of the patient.

75. I considered the relevance of the European Convention on Human Rights (ECHR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) in this regard. I specifically considered whether the length of wait endured by the patient was sufficient to engage Article 12 of the ICESCR, having already found the wait to be unacceptable. Article 12 outlines the '*right of everyone to the enjoyment of the highest attainable standard of physical and mental health'*. I also considered the NIHRC Inquiry paper. I note that the paper states, '*The right to the highest attainable standard of health is to be realised progressively over time and the State must use the maximum available resources to fulfil the right'*.

76. Express findings of a breach of any relevant laws are a matter for the courts to consider. However, by outlining the thinking behind these decisions, I hope to demonstrate the approach I take and the continued importance of equality and human rights considerations in the work of this office.

77. In relation to the impact the delay had on the patient, I note the Assembly research paper states, '*For many people, longer waits result in inconvenience and the discomfort associated with living with a medical condition. But for others their condition may deteriorate and a longer wait for treatment may cause them harm'.* I note the G IPA's advice that '*the MRI did not suggest any change in either the spread of the disease or its severity…on balance, the further increment in severity due to the delay is minimal'*. However, I also note that the ovarian cyst increased in size from 2.4cm to 8.2cm in December 2018. Furthermore, I note the G IPA's advice that '*the delay in surgical treatment has prolonged her [the patient's] pain and suffering. The delay may also reduce her*

chances of conception, and progressively impact on bowel and bladder function over time'. In addition, I also note the G IPA (2)'s advice that the Trust's failure to prescribe the patient appropriate medication while she awaited the surgery would have caused her to '*suffer from continuing symptoms which were likely to worsen as the disease progressed'.* I will refer to the injustice the patient experienced later in this report.

MRI imaging

78. The patient was concerned that the Trust reclassified an 'urgent' MRI request for her as 'routine'. She said her concern was that without an MRI, the Trust was unable to determine disease progression, as this would be the primary measurement that could potentially move her up the waiting list. I note that NICE NG73 recommends pelvic MRI '*to assess the extent of deep endometriosis involving the bowel, bladder or ureter'*. I also note that it asks clinicians to consider '*outpatient follow-up (with or without examination and pelvic imaging)*'. However, it does not specify whether the imaging ought to be done by MRI or ultrasound. Therefore, I am satisfied that there was no obligation on the Trust for it to undertake a further MRI for the patient at that time.

79. In relation to the classification of the MRI request from the patient's GP, I note the G IPA (2)'s advice that *'there was no evidence that here had been a significant change in the patient's symptoms which would indicate that the MRI should have been requested as urgent'*. Therefore, I accept his advice that '*it was appropriate to request the MRI as routine'*.

80. The patient explained that the Trust informed her that it would not be able to assess an MRI undertaken privately. I note that the Trust's Policy on the Management of Private Practice states that *'a patient who sees a Consultant privately may decide that he / she wishes any further treatment to be carried out by the Trust. The patient should then seek access to the Trust facilities by way of a referral from the Consultant'.* However, it does not provide any specific guidance on whether or not imaging undertaken privately can be considered or interpreted by clinicians within the NHS. I accept the G IPA's advice that '*it is…common practice amongst radiologists/radiology departments not to re-*

interpret results/reports from an external provider'. I consider that there is no evidence to support that the Trust's stance regarding this matter was incorrect or was not in accordance with relevant guidelines. I do not uphold this element of the complaint.

Referral to a specialist centre within the UK

81. The patient explained that the Trust did not refer her to a specialist centre within the mainland United Kingdom for the treatment she requires. She queried why the treatment did not qualify for an extra contract referral (ECR) when the required surgery is not available due to the cap currently in place.

82. I note that the HSCB Arrangements state that Trusts ought not to submit ECRs when the *'care or treatment which is provided or capable of being provided in Northern Ireland but is temporarily unavailable'*. I also note that the Trust explained that the treatment required '*is available in Northern Ireland, albeit the wait is protracted due to pressures highlighted above'*. I accept the patient's frustration with the lack of progress the Trust made on the particular waiting list she was on. However, I consider that the required treatment was available within Northern Ireland, albeit that it experienced significant delays. I consider that the criteria outlined in the HSCB Arrangements prevented the Trust from submitting an ECR for the treatment required. I do not uphold this element of the complaint.

Summary of findings

83. Although I have not upheld all of the patient's concerns, I identified a number of failings. I identified that the patient's wait for surgery was significant and unacceptable. I also identified that the Trust failed to invite the patient to attend outpatient appointments during her four year wait for surgery without being prompted to do so. Furthermore, I identified that the patient was not offered hormonal treatment to minimise the progression of the disease after she was placed on the urgent waiting list in September 2016.

84. The clinical records document that the size of the ovarian cyst increased considerably, causing the patient to experience pain and discomfort over a significant period. Furthermore, I consider that the failures may have had

implications on the complexity of the surgery required, and on her future health. I am satisfied that the failures identified caused the patient to experience the injustice of the loss of opportunity to have timely treatment to alleviate her symptoms. I am also satisfied that the delay in accessing the required treatment caused the patient to experience the injustice of uncertainty and distress.

CONCLUSION

85. I received a complaint about the care and treatment the Trust provided to the patient. The complaint related to the treatment of the patient's endometriosis.

86. The investigation identified failures in the care and treatment of the patient. It found that the delay in providing surgical treatment to the patient was significant and unacceptable. It also identified that the Trust failed to invite the patient to attend outpatient appointments during her four year wait for surgery without being prompted to do so. Furthermore, it found that the patient was not offered hormonal treatment to minimise the progression of the disease after she was placed on the urgent waiting list in September 2016.

87. I am satisfied that the failures identified caused the patient to experience the injustice of the loss of opportunity to have timely treatment to alleviate her symptoms. I am also satisfied that the patient experienced the injustice of uncertainty and distress.

88. The investigation did not find maladministration in the Trust's decision not to interpret private practice MRI reports. It also did not find maladministration in the Trust's decision not to submit an ECR for the treatment required by the patient.

Observations

89. I acknowledge that in Northern Ireland protracted waiting times are not unusual, in a system where the demand for gynaecology services greatly outweighs the capacity available. I accept this is a much wider issue that is outside the scope of this specific complaint. The Assembly Research Paper reported that as of December 2018, 22,350 patients in Northern Ireland were waiting more than 52

weeks for their inpatient/day case procedure. It is therefore unsatisfactory that the patient has waited more than one year for her procedure. However, it is not exceptional.

90. I considered the relevance of the ECHR and ICESCR in relation to this complaint. Express findings of a breach of any relevant laws are not matters for me to consider. However, I cannot consider such extraordinary times to be acceptable. I note ICESCR Article 12 guarantees the right of everyone to the enjoyment of the highest attainable standards of physical and mental health. While this is not an absolute right to be healthy, there is an expectation that the highest attainable standard of health is realised progressively over time with the maximum available resources devoted to fulfil the right to health. It appears there is little doubt that individuals suffer considerably while they wait and this therefore engages ECHR Article 8 rights. This is not a criticism of individuals working within our health system. However, urgent action is necessary, as has been recognised for some time, to address the very long waits that individual citizens experience.

Recommendations

91. I recommend within **one** month of the date of this report:
    i. The Trust provides the patient with a written apology in accordance with NIPSO 'Guidance on issuing an apology' (June 2016), for the injustice caused as a result of the failures identified; and
    ii. The Trust provides to the patient a payment of £500 for the injustice experienced.

92. I further recommend that the Trust implements an action plan to incorporate the following recommendation and should provide me with an update within **three months** of the date of my final report. That action plan is to be supported by evidence to confirm that appropriate action has been taken (including, where appropriate, records of any relevant meetings) to:
    i. Undertake an audit to include a review of a random sample of relevant patient records. These records ought to be benchmarked against paragraph 1.86 (hormonal treatment) of NICE NG73. The Trust ought to include any recommendations identified in its update

to this office.

93. The investigation established that Trusts can refer patients diagnosed with Stage III and Stage IV endometriosis to other Trust areas within Northern Ireland for treatment. However, it identified that at the time the patient required her treatment, the Trust was unaware it could transfer her care to allow the patient to obtain treatment earlier. While I did not identify a failing in this instance, I would ask the Trust to consider undertaking a review of its relevant policies to ensure that consideration is given to the referral of those patients diagnosed with Stage III and IV endometriosis to accredited centres in other Trust areas within Northern Ireland.

MARAGARET KELLY
Ombudsman **February 2021**

Appendix 1

PRINCIPLES OF GOOD ADMINISTRATION

Good administration by public service providers means:

1. Getting it right

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

2. Being customer focused

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to its commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

3. Being open and accountable

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.
- Stating its criteria for decision making and giving reasons for decisions
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for its actions.

4. Acting fairly and proportionately

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

5. Putting things right

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

6. Seeking continuous improvement

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.