Northern Ireland
Public Services
Ombudsman

Investigation Report

Investigation of a complaint against the Belfast Health and Social Care Trust

NIPSO Reference: 19688

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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

I received a complaint about how the Belfast Health and Social Care Trust managed a complainant's appointments at the Macular Service, and how it failed to properly respond to her phone call of 22 November 2017.

The investigation identified that the Trust's PAS system did not allow for dual registration on the system for a face to face medical review and a clinic appointment for imaging and injection/treatment. This caused a delay in the complainant receiving treatment for her age related macular degeneration. The delay in the complainant's regular injections meant that her eyesight deteriorated to below the legal driving limit, which has affected her ability to perform activities of daily living.

The investigation also identified a failure to properly record and respond to a phone call made by the complainant on 22 November 2017. I consider this failure amounted to maladministration.

The Trust have identified and implemented a number of improvements which has meant that I have not needed to make recommendations for service improvement. However I made recommendations for an apology and consolatory payment to the complainant for the injustice that she suffered.

THE COMPLAINT

1. The complaint concerned the Belfast Health and Social Care Trust's (the Trust) failure to properly manage the complainant's appointments for her Age Related Macular Degeneration[1].

2. Specifically, the complainant said she did not receive an appointment at the Macular Service from 28 June 2017 to 9 January 2018, when she had typically received appointments every eight weeks. She said that this delay in treatment resulted in a significant deterioration in her eyesight. She also complained that the Trust failed to give her a proper explanation as to why she did not receive a follow up appointment for seven months.

Issues of complaint

3. The issue which I accepted for investigation was:

   Issue 1: Was the management of the complainant's macular degeneration appointments appropriate and in accordance with relevant standards?

INVESTIGATION METHODOLOGY

4. 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 raised by the complainant. This documentation included information relating to the Trust's handling of the complaint.

Independent Professional Advice Sought

5. After further consideration of the issues, I obtained independent professional advice from an independent professional advisor (IPA):

6. The information and advice which have informed my findings and conclusions are included within the body of my report. The IPA provided 'advice'; however how I have weighed this advice, within the context of this particular complaint,

[1] a degenerative condition affecting the central part of the retina (the macula) and resulting in distortion or loss of central vision

is a matter for my discretion.

Relevant Standards.

7. 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.

8. The general standards are the Ombudsman's Principles[2]:
    - The Principles of Good Administration;
    - The Principles of Good Complaints Handling; and
    - The Principles for Remedy.

9. 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.

10. I have considered the following relevant policies:
    - National Institute for Health and Care Excellence Guideline: "*Age related macular degeneration*" (Published January 2018), (2018 NICE Guidelines);
    - National Institute for Health and Care Excellence Technology Appraisal Guidance*: "Aflibercept[3] solution for injection for treating wet age-related macular treating wet age-related macular degeneration*" (Published July 2013) (2013 NICE Guidance);
    - National Institute for Health and Care Excellence Guideline Guidance: "*Ranibizumab[4] and pegaptanib[5] for the treatment of age-related macular degeneration*": (Published: 27 August 2008) (2008 NICE Guidance);
    - Royal College of Ophthalmologists: '*Age Related Macular Degeneration: Guidelines for Management'* (Published September 2013). (2013 RCO Guidelines); and

[2] These principles were established through the collective experience of the public services ombudsmen affiliated to the Ombudsman Association.
[3] Aflibercept is a biopharmaceutical drug approved for the treatment of wet macular degeneration.
[4] An Anti-VEGF drug suitable for the treatment of Wet ARMD. Also known as Lucentis.
[5] An anti-angiogenic medicine for the treatment of neovascular (wet) ARMD.

- Belfast Health and Social Care Trust, Patient Administration System *'PAS Guidance for recording Macular Injection Review Patients'* (Published May 2018) *(*2018 PAS Guidance).

11. I have not included all of the information obtained in the course of the investigation in this report but I am satisfied that everything that I consider to be relevant and important has been taken into account in reaching my findings.

12. As part of the NIPSO process, a draft copy of this report was shared with the Trust and the complainant for comment on the factual accuracy and the reasonableness of the findings and recommendations.

THE INVESTIGATION

Issue 1: Was the management of the complainant's macular degeneration appointments appropriate and in accordance with relevant standards?

Detail of Complaint.

13. The complainant said that following her 28 June 2017 appointment at the Macular Service, she was not seen again until 9 January 2018, despite usually being seen approximately every eight weeks. She complained that she called the Macular Service in November 2017 and informed them that her eyesight was deteriorating rapidly, but was not offered an appointment until 9 January 2018. She said that by the time she attended her 9 January 2018 appointment, the delay in treatment had already caused a significant deterioration in her eyesight, affecting her activities of daily living. She complained that the deterioration between June 2017 and January 2018 meant that she was no longer able to drive.

14. She also complained that the Trust never offered her a proper explanation for the delay in her treatment. She complained that she was initially told this was caused by a problem with the Patient Administration Systems (PAS) booking system used by the Macular Service, but was subsequently told that her delayed appointment was due to staff shortages. She did not accept the Trust's explanation that staff shortages were the cause of her delayed appointment.

Evidence Considered.

Relevant Policies and Procedures.

15. The 2008 NICE Guidance states:
    - Paragraph 2.1. '*Age-related macular degeneration (AMD) is an eye condition that leads to a progressive loss of central vision. People retain some peripheral vision, but the ability to see well enough to recognise faces, drive and read is affected, and vision can deteriorate rapidly*';
    - Paragraph 4.3.12: *'The Committee…noted that the model assumed that the individualised dosing would result in stable visual acuity for the majority of the patients, with a mean of 8 injections required in the first year followed by a mean of 6 injections in the second year.'*

16. Paragraph 4.5 of the 2013 NICE Guidance states: *'The Committee… noted that aflibercept at its licensed dose was shown to be clinically non-inferior to ranibizumab in terms of visual acuity outcomes at 96 weeks. The Committee concluded that aflibercept is a clinically effective treatment option for visual impairment caused by wet age-related macular degeneration.'*

17. The 2013 RCO Guidelines state: *'Patients should be advised of the need for frequent monitoring when commencing a course of intravitreal[6] drug treatment for AMD. This will be every 4-8 weeks depending of the licensed anti-VGEF[7] used. Treatment and follow up may need to be continued for up to and beyond 2 years.'*

18. The 2018 NICE Guidelines state:
    - Paragraph 1.5.1: *'Offer intravitreal anti-VEGF treatment for late AMD (wet active) for eyes with visual acuity within the range specified in recommendation 1.5.6'*
    - Paragraph 1.7.8: *'Offer people with late [ARMD] (wet active) ongoing monitoring with OCT[8] for both eyes'.*

[6] Intravitreal is a route of administration of a drug, or other substance, in which the substance is delivered via an eye.
[7] Anti–vascular endothelial growth factor therapy, also known as anti-VEGF therapy or anti-VEGF medication, is the use of medications that block vascular endothelial growth factor. This is done in the treatment of ARMD.
[8] Optical coherence tomography is a non-invasive imaging tool used to diagnose and monitor the progression of retinal and optic nerve diseases,

19. The 2018 PAS Guidance was introduced in May 2018 and provides guidance to Trust staff in how to enter patients on Dual waiting lists. It states *'[a]t present, a patient cannot be added to two Waiting Lists within a single registration on PAS. In order to ensure that patients are managed correctly on the Macular review waiting lists, a separate outpatient registration should be opened for the Macular injection.'*

Trust's response to investigation enquiries.

20. The Trust stated the complainant was scheduled to be seen eight weeks after her injection on 28 June 2017, but *[t]his review regrettably did not take place until 9 January 2018 due to a reduction in the number of available medical staff who could provide this level of care.'* The Trust explained *'[d]uring 2017, at the Macular Service, an individual patient could only be actively registered on one waiting list at a time. Therefore in June 2017 [the complainant] was listed on the medical review waiting list and could not receive an injection/treatment until [she] had a review.'* The Trust also stated that *'during the latter part of 2017, there was a considerable reduction in the level of medical staff working within the Macular Service and this negatively affected the waiting times for patients to receive medical reviews.'*

21. In relation to the staff who perform injections and medical reviews, the Trust advised '*[w]hen the Macular Service was established ten years ago medical staff, who were mostly consultants, saw all patients. With demand significantly increasing year on year, through an increase in new referrals as well as the increasing burden of patients under active on-going treatment, the service had to continually evolve and to develop new ways of working.'* One such development was to *'upskill a number of additional non-medical staff to safely deliver services and treatments whilst the patient remains under the care of a specialist consultant at all times.'*

22. The Trust stated it experienced a reduction in staff who were able to conduct reviews '*from the period January 2017 to September 2017, with the loss of a Locum Appointment Service (LAS) post in January 2017, the retirement of a consultant ophthalmologist in April 2017 and loss of a clinical fellow in July 2017, who all specialised in macular degeneration services.'* Unfortunately, the

Trust *did not have a replacement consultant ophthalmologist in post until December 2017… and appointed two LAS posts in December 2018'.* The Trust explained that when the complainant called in November 2017, she *'was still active on a waiting list.'*

23. The Trust explained *'[t]he Macular Service were working with the PAS managerial team in February 2018 to amend the Trust PAS management direction, which required that patients could only be listed on one active waiting list at a time within the Macular Service. The Macular Service sought and was subsequently allowed to have dual list registrations running simultaneously for injection and review waiting lists.'*

24. Regarding the complainants call to the service in November 2017, the Trust stated it '*has no written record of the complainant informing the staff by telephone that her eyesight was deteriorating further in November 2017.* Since her complaint *'a procedure was put in place in the Macular Service on 28 March 2018 to record telephone queries of this nature. When a patient informs the administration team of, for example a decrease in visual function, this query is recorded by the receptionist and the patient is advised that the senior nurse on duty will call them back.'*

25. Regarding her complaint about not being offered the chance to speak with a member of the nursing staff when she called in November 2017, the Trust stated that it is *'very sorry that [the complainant] was not offered this opportunity.'* The Trust also stated *'it is clinically difficult to attribute the review delay alone as the causative factor for the visual decline experienced by [the complainant].'*

26. In follow up correspondence, the Trust acknowledged the complainant's macular degeneration appointments *'did fall short of [its] expectations, as [the complainant] did not receive an 8 week appointment as indicated at her attendance on 28 June 2017.'* In relation to any applicable NICE Guidelines, the Trust stated '*these do not provide examples of review time targets'.*

27. The Trust explained that *'[i]n [the complainant's] case, there was a query raised about driving standards during her appointment on 28 June 2017. It was for this reason [the complainant] was placed on a management plan of a face-to-*

face review'. The Trust also explained that it has now introduced a dual registration system and that '*[the complainant] would have been a perfect example of a patient that required dual registration… One registration was required to discuss driving standards, a second registration was required for an imaging clinic appointment (to have visual acuity assessed, scans of each eye done and a decision if an injection was required or not, all the while awaiting her face to face review appointment with a consultant.'*

28. In relation to the PAS system, the Trust explained that the entry on the system from 22 November 2017 means that the complainant was booked from the AMD review waiting list by a staff member on 22 November 2017 at 11:17 for her appointment to attend on 9 January 2018 at 10:00.

29. The Trust provided a copy of an email sent on 22 February 2018 regarding the '*[u]se of two waiting lists'*. The Trust explained that the purpose of this email was to request the PAS management team implement *'dual list registrations running simultaneously for injection and review waiting lists'.*

30. In its response, the Trust also apologised that the complainant was not offered the opportunity to speak with a member of the nursing staff when she called in November. The Trust also stated that as a result of her complaint, *'a procedure was put into place in the Macular Service on 28 March 2018 to record telephone queries of this nature.'* Under the new system, enquiries are emailed to the nurse in charge for that day who then *'telephones the patient and verbally assesses their symptoms and advised accordingly.'*

Clinical Records

31. The complainant's records indicate that she had been a patient of the Macular Service since 2013. She was diagnosed with wet ARMD on 29 August 2013. Since then, she was on a treatment plan that included regular reviews and injections of Lucentis into both eyes.

32. On 28 June 2017, the complainant attended at the Macular Service and was seen by an Associate Specialist Ophthalmologist. Her visual acuity was noted

to the 5/60[9] best corrected in her right eye and 6/15 best corrected in her left eye. She was given a Lucentis injection in each eye, and was scheduled for *'a follow up appointment with a doctor in approximately 4 weeks in the Macular Clinic.'* The records from this date note *'Patient states she is still driving – Advised patient that our Visual Acuity shows vision is below the driving standard, but she should attend own optician for an assessment. Patient states she attended optician within the last month and her optician and DVLA are aware of her vision.'* In addition to having a follow up appointment for a face to face with a doctor in four weeks, the plan was also noted to be for a *'bilateral Lucentis [injection] then back for review 8 weeks to reassess for driving.'*

33. The complainant was not seen in four or eight weeks. She was next seen on 9 January 2018. Her vision was noted to be 6/60 best corrected in her right eye and 5/60 best corrected in her left eye. She again received Lucentis injections in her eyes. On clinical examination, she was noted to have a 'loss of >5 ETDRS[10] letters since last visit'. The complainant met with the Consultant Ophthalmologist who documented *'Bilateral [wet ARMD] and cateracts. Reports deterioration in vision since last seen. Has been upset at length of time since last seen.'* The Consultant Ophthalmologist noted that he *'agreed to look into why her review was so delayed and let her know...She knows that she should not be driving: that she has failed the driving [visual acuity] level today by a long way. We discussed the legal limits and she has previously informed DVLNI. She knows VA may never improve to driving levels'.*

34. On 13 March 2018, the Consultant Ophthalmologist informed the complainant that his *'expectation is of no further improvement in vision'*

35. On 27 September 2018 the complainant saw another Consultant Ophthalmologist who noted her visual acuity at 6/48 in her right eye and 6/60 in her left eye, best corrected. This consultant noted that he *'[d]iscussed at length patient's concerns over management...now set up for dual waiting lists for injection and review to avoid delays of patients booked for review'.*

[9] d/D where: d = distance at which the letters are read. D = distance at which the letter should be read by normal person. This is a typical snellen's chart used for testing visual acuity
[10] ETDRS stands for Early Treatment Diabetic Retinopathy Study. TDRS acuity testing has become the worldwide standard for visual acuity testing

36. As of 9 November 2018, the clinical records indicate that the complainant vision remains 6/48 best corrected in her right eye and 6/60 best corrected in her left eye.

Independent Professional Advice.

37. In considering this issue of complaint, I obtained advice from an Independent Consultant Ophthalmic Surgeon Advisor (IPA). This IPA advised that *'[t]he underlying cause of [ARMD] is still unknown.'* The IPA described 2 basic forms of ARMD*, '[d]ry, or atrophic' and '[n]eovascular, or wet'.* The IPA advised that in many cases neovascular ARMD can be treated *'very effectively with intravitreal [anti-VEGF] agents injected into the eye. These agents have been widely available since 2008 when tagged NICE Technology Assessment Guidance obliged NHS funding organisations to provide them. There has been further NICE guidance since 2012, 2013 and in February 2018.'*

38. Regarding the efficacy of treatment, the IPA advised *'[t]reatment is successful in stabilizing vision in approximately 92% of cases and given a 3 Snellen line [15 letter] gain in up to about 30 % of cases. Longterm studies confirm that this improvement or stabilization is maintained for years. This is provided patients have regular review with OCT and repeated injections.'* Although the IPA also advised *'even with the best observations and treatment, some patients do suffer recurrences and loss of vision even after initially successful treatment. In addition progression of coexisting dry [AMRD] can cause further visual loss.'*

39. In relation to the applicable NICE Guidance, the IPA advised the '*essential guidance remains unchanged from 2012.'* The IPA advised '*failure to review [the complainant] from at the latest September 2017 until January 2018 was in breach of this guidance and good practice in the treatment of neovascular ARMD.'* The IPA advised that the complainant should ideally have had further injections in both eyes '*at most about 8 weeks after her last injections on the 28 June 2017.*' The IPA advised as the complainant '*did not receive injections until 8 January 2018, the delay was therefore 4 months which was not acceptable'*.

40. The IPA was asked to comment on whether the delay in treatment caused the complainant's vision to deteriorate. The IPA advised *'[o]n balance of*

probabilities, the delay was the major contributor to the drop in vision from 6/15-6/18 with glasses up to June 28 2017 to 6/48 with glasses on 8 January 2018. Failure to give further injections in August/September 2017 deprived her of the best chance of retaining the central vision that she had in June 2017 for as long as possible.' The IPA advised that since January 2018, the complainant's *'vision has improved slightly since then and has stabilized at 40 letters [6/48] in the right eye and 33 [6/60] in the left eye, both with glasses.'*

41. The IPA advised that *'Progression of the dry ARMD may well have contributed to the decline to an undefinable extent. I cannot comment on the degree (if any) to which a possible increase in cataract contributed to her loss in vision.'* However the IPA also advised that the marked deterioration after June 2017 *'was on the balance of probabilities largely due to the delay in treatment'.*

42. Although the IPA was clear that, on balance of probabilities, the delay in receiving injections contributed to her reduced visual acuity, the IPA advised that *'[f]rom January 2017 to June 28 2017, the records [he reviewed showed] that her vision was well below the limit required on 3 of the 4 occasions that it was tested. On one occasion it was recorded at 6/12 which is the minimum level required to drive legally. This was discussed with [the complainant] and was the reason for the booked "face to face" appointment.'* The IPA advised *'based on the detailed evidence [he] had seen, [the complainant's] vision was below the legal limit to drive from January 2017.'*

43. The IPA advised that the complainant only met the visual acuity standards set by the DVA *'on one of 4 examinations between January and June 2017.'*

44. The IPA advised that the complainant appointments were not managed in a manner consistent with good medical practice. According to the IPA, *'[*the complainant] *should have been reviewed with OCT imaging and had further injections within at most 8 weeks. The review and treatment intervals should only have been increased gradually if the bruising and swelling was not recurring.'* The IPA also advised that the complainant's phone call was not managed appropriately as it was not *'acted upon promptly'.*

45. The IPA identified several issues where the Trust could develop learning. The IPA advised that the Trust should '*[e]stablish a failsafe system to ensure that*

patients on the ARMD treatment pathway remain under review at appropriate intervals' and 'ensure that patients are not taken off this pathway for any reason without clinical authorization by appropriately qualified clinicians.'

46. Regarding the Trust's failure to properly respond to the complainant's follow up phone calls, the IPA advised the Trust should *'[d]evelop a system for recording and responding appropriately to telephone calls or any communications from patients enquiring about appointments.'*

47. In conclusion, the IPA advised that following her injection on 28 June 2017, '[*t]here was a seven month gap before further injections. This delay was a major contributor to the vision in her left and better eye dropping to Logmar* [11]*0.90 (Snellen 6/48). She should have been reviewed within about 8 weeks… This has left [the complainant] severely visually impaired, unable to read except with great difficulty and with considerable problems with normal activities of daily living.'*

48. The IPA advised that the Trust put in place certain improvements to its processes. These were:

> *'Establish failsafe system to ensure that patients on the ARMD treatment pathway remain under review at appropriate intervals.'*
>
> *'Ensure that patients are not taken off this pathway for any reason without clinical authorisation by appropriately qualified clinicians.'*
>
> *'Develop a system for recording and responding appropriately to telephone calls or any communications from patients enquiring about appointments'*

49. The Trust have accepted the advice of the IPA. The Trust *'acknowledges and wishes to apologise to [the complainant] that due to a delay in her appointment in 2017 she suffered a decrease in her visual ability, which has negatively impacted on the challenges she encounters with routine activities of daily living.'* The Trust reiterated the steps that had been taken since the complainant's appointment to improve its services, including the improvements to the PAS system and the Telephone query management system.

[11] ETDRS Chart. These terms are interchangeable.

Responses to Draft Report.

50. The Trust accepted the proposed findings of the draft report.

51. The Investigating Officer met with the complainant to discuss the proposed findings. The complainant provided a statement expressing her regret that she had *'given the impression that [she] hold[s] the seven month gap in treatment wholly responsible for [her] having to give up driving. [she] does not.'* The complainant explained she has *'always been aware of the level of her eyesight in relation to driving. Right from the beginning, when [she] was referred to the Macular Clinic, [she] notified the DVLA as she was required to do, who subjected her to frequent and rigorous testing with multiple examiners before granting her a license.'* The complainant believes that her eyesight was *'hovering over the borderline'* before the delay in treatment, but *'during the seven month gap in [her treatment], the damage sustained by her eyesight was so severe (mainly in the left eye) that [her vision] plunged to the bottom of the chart and never recovered.'* The complainant stated her eyesight is '*borderline no longer'.*

Analysis and Findings

52. I carefully considered this complaint. I note the complainant was confused by the Trust's explanations why her appointment was delayed and has complained that the Trust told her initially that the delay in her appointment was due to an IT system failure, but subsequently attributed the delay to staff shortages. The complainant has also complained that the Trust did not properly respond to her phone call in November 2017, where she complained about her deteriorating eyesight. I also note that the complainant believes the delay in treatment caused her vision to deteriorate. In considering the complaint, I have focussed on the Trust's scheduling of the complainant's follow up appointment and how the Trust managed the complainant's November phone call enquiring about her follow up appointment.

Scheduling the complainant's follow up appointment.

53. In considering the complaint, I note the Trust have acknowledged that its management *did fall short of [its] expectations, as [the complainant] did not*

receive an 8 week appointment as indicated at her attendance on 28 June 2017'. The IPA advised that '*[the complainant] should have been reviewed with OCT imaging and had further injections within 4-6 weeks and at most within 8 weekly intervals.'* Accordingly, it is undisputed that the complainant should have had a further appointment within eight weeks. It is also undisputed that the complainant did not receive a follow up appointment for approximately seven months.

54. I have considered the cause of the seven month gap in treatment from June 2017 to January 2018. According to the clinical records, I note that the complainant was to have two follow up appointments after her 28 June 2017 appointment. One appointment was for *'a follow up appointment with a doctor in approximately 4 weeks in the Macular Clinic' b*ecause of '*a query raised about driving standards during her appointment on 28 June 2017.'* In addition to a face-to-face with the doctor, the complainant was also scheduled for her *'bilateral Lucentis [injection] then back for review 8 weeks to reassess for driving.'*

55. The Macular Service's records establish that the plan was for the complainant to have two follow up appointments; one for the face-to-face to assess and discuss her ability to drive and another for her follow-up injection, both of which should have been completed within eight weeks. I accept the advice of the IPA that *'the decision to review in 8 weeks made on 28 June 2017 was correct'.* As the clinical records indicate an appropriate treatment plan for an eight week review, I have not found any failure in care and treatment in relation to the clinical decisions made on 28 June 2017.

56. I considered the Trust's explanation that the complainant's appointment was delayed because patients of the macular service '*could only be actively registered on one waiting list at a time'.* The Trust indicated that the PAS system at that time would not allow a patient to be registered on dual waiting lists, stating that '*[the complainant] was listed on the medical review waiting list and could not receive an injection/treatment until [she] had a review.'* The Trust has acknowledged '*[the complainant] would have been a perfect example of a patient that required dual registration.'* Unfortunately, the PAS system in place at the time would not accommodate the complainant being placed on two

waiting lists.

57. Accordingly, the PAS system would not allow the complainant to receive a follow up treatment appointment until she had her face to face review with a doctor. Although the treatment plan for the complainant was to receive a review by a consultant, this was not done within four weeks as recommended by the Associate Specialist Ophthalmologist on 28 June 2017. The Trust's position is that this delay was caused by staff shortages. I considered the Trust's explanation that *'during the latter part of 2017, there was a considerable reduction in the level of medical staff working within the Macular Service and this negatively affected the waiting times for patients to receive medical reviews.'*

58. I considered the Trust's further explanation that '*from the period January 2017 to September 2017, with the loss of a Locum Appointment Service (LAS) post in January 2017, the retirement of a consultant ophthalmologist in April 2017 and loss of a clinical fellow in July 2017, who all specialised in macular degeneration services.'* I note the Trust's statement that it '*did not have a replacement consultant ophthalmologist in post until December 2017… and appointed two LAS posts in December 2018'.*

59. I accept the advice of the IPA that '[the complainant] *should ideally have had further injections in both eyes at most about 8 weeks after her last injections on the 28 June 2017. She did not receive injections until 8 January 2018.'* I have also accepted the conclusion of the IPA, who advised *['t]he delay was therefore four months, which was not acceptable'.* I reviewed the evidence of the remedial measures taken by the Trust in the form of the 22 February 2018 email to the PAS management team and the 2018 PAS Guidance issued by the Trust. I am satisfied that this evidence establishes that the initial failure in scheduling the complainant's appointment was caused by the PAS system's inability to register patients on dual waiting lists. However, I am concerned that this issue with the PAS system was not appreciated before the complainant experienced a four month delay in her treatment, particularly in light of the known staffing issues within the Macular Service.

60. The first and second principle of good administration, getting it right and being

customer focused, requires the Trust to **'***take proper account of established good practice*' and '*ensure people can access services easily'*. Although staff shortages may have played a part in delaying the complainant's face-to-face review, the PAS systems should have allowed for the complainant to continue to receive her regular, eight weekly treatments while awaiting her face-to-face review with a doctor which was for a different purpose. I consider that the Trust failed to properly ensure that it had a system in place that could adequately accommodate the needs of patients, such as the complainant. It appears to have only been a matter of time until this flaw in the system affected a patient's appointments and had a significant impact on a patient's care and treatment. I am concerned that the Trust unfortunately failed to identify this flaw before the complainant's care and treatment was so significantly impacted. I find that the Trust failed to properly manage the complainant's Macular Service appointments and this failing constitutes maladministration. The maladministration in the management of appointments resulted in a failure in the complainant's care and treatment resulting in a delay in excess of four months in receiving the necessary injections for her wet ARMD. As the IPA has noted, on the balance of probabilities this caused a permanent deterioration on the complainant's central vision.

The Trust's response to the complainant's phone call in November 2017.

61. The complainant said that she called the Trust sometime in November to enquire about why she had not received a follow up appointment. Due to the staff shortages within the Macular Service, the complainant face-to-face review appointment had still not occurred by the time she called in November of 2017. She complained that despite indicating that her vision had gotten worse, she was not offered the chance to speak with a nurse or doctor and was told she would not be seen until January at the earliest.

62. The Trust states it has no record of this conversation. However, I reviewed the PAS entries and note that an entry on 22 November 2017 records that the complainant was '*Booked from Waitlist'* on this date, for an appointment on 8 January. On the balance of probabilities, I conclude that this entry was likely made as a result of the complainant's phone call. I can see no other reason for

a member of staff to have made this entry.

63. I note that the Trust has expressed regret that the complainant was not offered the opportunity to speak with a member of the nursing staff when she called in November. I have considered the IPA's advice that 'the complainant's phone call was not managed appropriately as it was not *'acted upon promptly'.*

64. The second principle of good administration, being customer focused, requires the Trust *'deal with people helpfully, promptly and sensitively, bearing in mind their individual circumstances'* and to respond '*to [patients] needs flexibly'*. I note that the Trust and the IPA both agree that the complainant's phone call was not managed appropriately in that her concerns were not addressed promptly and she was not offered the opportunity to speak with a nurse. I find that the Trust's should have had a system in place to ensure calls of this nature were promptly escalated to appropriate medical or nursing personnel. Accordingly, I find that the Trust failed to properly respond to the complainant's 22 November phone call and that this failure constitutes maladministration.

65. I commend the Trust for acknowledging its failures. I considered the IPA's advice that the Trust *'[d]evelop a system for recording and responding appropriately to telephone calls or any communications from patients enquiring about appointments.'* I note the Trust has already sought to do this, indicating that *'a procedure was put into place in the Macular Service on 28 March 2018 to record telephone queries of this nature.'*

66. I have also considered the IPA's advice that the Trust '*establish a failsafe system to ensure that patients on the ARMD treatment pathway remain under review at appropriate intervals.'* The Trust indicated that it has now put in place a new PAS system allowing patients to be recorded on dual waiting lists.

67. The fifth and sixth principles of good administration, putting things right and seeking continuous improvement, require the Trust '*put mistakes right quickly and effectively'* and ensure the Trust '*learns lesson from complaints and uses these to improve services and performance*.' The Trust has acted in accordance with these principles in putting in place an improved procedure for handling patient phone calls and a new PAS system which allows patients to be on dual waiting lists.

68. However, it is unfortunate that the Trust did not appreciate these deficiencies in its processes before the complainant experienced over a four month delay in her treatment and loss of central vision.

The impact of the Trust's failings on the complainant.

69. The complainant said that the gap in treatment caused her vision to deteriorate dramatically. She stated she can no longer drive and has also suffered a reduction in her activities of daily living, including her ability to read and write, manage her own affairs, manage mail, or use a computer. She complained that she lives alone and the impact to her eyesight has made it difficult for her to maintain her independence.

70. I considered the Trust's position that *'it is clinically difficult to attribute the review delay alone as the causative factor for the visual decline experienced by [the complainant].'* The IPA was asked to provide advice about whether, on the balance of probabilities, the delay in treatment caused any deterioration to the complainant's eyesight. I note that the complainant was receiving treatment for Wet ARMD (also known as Neovascular ARMD). I accept the IPA's advice that in many cases Neovascular ARMD can be treated *'very effectively with intravitreal [antiVEGF] agents injected into the eye.'* In support of the efficacy of this treatment, the IPA referenced the 2008, 2012, 2013, and 2018 NICE Guidance, noting *'[t]reatment is successful in stabilizing vision in approximately 92% of cases and given a 3 Snellen line [15 letter] gain in up to about 30 % of cases. Longterm studies confirm that this improvement or stabilization is maintained for years… [antiVEGF] agents have been widely available since 2008 when tagged NICE Technology Assessment Guidance obliged NHS funding organisations to provide them.'*

71. I accept the IPA's advice that, on balance of probabilities, the delay in treatment *'has left [the complainant] severely visually impaired, unable to read except with great difficulty and with considerable problems with normal activities of daily living.'*

72. Regarding her complaint that she is no longer able to drive as a result of the delay in treatment, I note that the complainant believes there has been some misunderstanding about her complaint. In response to the draft report, the

complainant stated she believed her eyesight was '*borderline'* before the delay in treatment. I considered the IPA's advice that *'[f]rom January 2017 to June 28 2017, the records [he reviewed showed] that her vision was well below the limit required on 3 of the 4 occasions that it was tested. On one occasion it was recorded at 6/12 which is the minimum level required to drive legally. This was discussed with [the complainant] and was the reason for the booked "face to face" appointment.'*

73. Although the complainant believes her vision was '*borderline'* before the delay in treatment, it appears that on the balance of probabilities, the complainant's vision was already below the legal standard required for driving. I accept the IPA's advice that *'based on the detailed evidence [he] had seen, [the complainant's] vision was below the legal limit to drive from January 2017.'* Though I note the complainant has indicated that she had advised the DVLNI of her eyesight issues and was being regularly tested.

74. I considered the impact to the complainant as a result of the Trust's failure to properly manage her appointments. I cannot conclude that the delay in treatment caused the complainant to lose her ability to drive. However, I consider that on the balance of probabilities, the delay resulted in her experiencing a loss of central vision, distress and a significant impact on her ability to carry out activities of daily living, which is likely permanent in nature.

CONCLUSION

75. The complainant submitted a complaint concerning how the Trust managed her appointments at the Macular Service and how the Trust failed to properly respond to her phone call of 22 November 2017.

76. I investigated her complaint and have found maladministration and failures in care and treatment in relation to the following:

    (i) Failing to properly manage the complainant's Macular Service appointments; and

    (ii) Failing to properly respond to the complainant's 22 November 2017 phone call.

77. I am satisfied that the maladministration and failure in care and treatment I identified caused the complainant to experience a significant injustice which has had a permanent impact to her activities of daily living.

Recommendations

78. I considered the injustice experienced by the complainant as a result of the Trust's failure to properly manage her appointments. Although the Trust acknowledged its failings and has already taken steps to improve its processes, the impact to the complainant is significant, having caused a permanent deterioration in her vision. I therefore consider the Trust should:

(i) Issues the complainant with an apology in accordance with the NIPSO guidance on apology. This is for the failings identified in this report, and should be issued within **one month** of the date of my final report.

(ii) Provides the complainant with a payment of £1000 by way of solatium for redress in respect of the distress and injustice identified above within **one month** of the date of my final report.

Paul McFadden
Acting Ombudsman **5 March 2020**

Appendices

APPENDIX ONE

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.