



Decommissioning of Lower Back Pain Procedures in Hillingdon

The patient experience

November 2018

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Introduction

Healthwatch Hillingdon

Healthwatch Hillingdon is a health and social care watchdog. We are here to help our residents get the best out of their health and care services and give them a voice to influence and challenge how health and care services are provided throughout Hillingdon. Healthwatch Hillingdon has very strong operational relationships with the local NHS, Hillingdon Council and Voluntary Sector organisations. We are an independent partner and a valued ‘critical friend’ within health and social care.

Membership of the Hillingdon Health and Wellbeing Board and Hillingdon Clinical Commissioning Group Governing Body enables us to have considerable strategic input into the shaping of local commissioning and the delivery of services.

As a local partner, we are kept well-informed, can challenge, and seek assurances on behalf of our residents, ensure that the lived experience of patients and the public are clearly heard, and are influencing decisions and improving health and social care in Hillingdon.

Our Reports and Recommendations

Healthwatch Hillingdon produces evidence-based reports for commissioners and providers, to inform them of the views and experiences of people who use health and social care services in the London Borough of Hillingdon.

Commissioners and providers must have regard for our views, reports and any recommendations made and respond in writing to explain what actions they will take, or why they have decided not to act.¹

Healthwatch have a duty to publish reports they share with commissioners and providers, and their responses, in public.

- Our reports and recommendations are also shared with:
- Hillingdon Health and Wellbeing Board
- Hillingdon External Services Scrutiny Committee
- Healthwatch England
- The Care Quality Commission

¹ Section 221 [3A] and Section 224 of The Local Government and Public Involvement in Health Act 2007 and implemented by “The arrangements to be made by Relevant Bodies in Respect of Local Healthwatch Regulations 2013.” (28 March 2013)

Executive Summary

In 2017, the eight North West London Clinical Commissioning Groups² approved two new policies for the management of low back pain, which took effect on 1st April 2018.

The introduction of the Acupuncture Policy (Appendix 1) and the Low Back Pain and Sciatica Policy (Appendix 2) resulted in the decommissioning of acupuncture, for all interventions, and several spinal injection treatments.

This report outlines the experience of The Hillingdon Hospitals NHS Foundation Trust patients, following the implementation of these policies in Hillingdon.

The eight North West London Clinical Commissioning Groups work together to manage their Planned Procedures with a limited Threshold (see page 7) and Individual Funding Requests.³ They have established a joint Policy Development Group to determine which procedures have limited thresholds and agree the clinical criteria policy for each of these.

Following updated guidance published by the National Institute for Clinical Excellence (NICE)⁴ in 2016, the Policy Development Group developed new policies for the treatment of Low Back Pain.

These were collectively approved at the North West London Clinical Commissioning Groups' Collaboration Board (now Joint Committee) in October 2017 and adopted on 1st April 2018.

As a member of the Policy Development Group, Healthwatch Hillingdon recognised that the NICE lower back pain guidance was evidence based and reasonable, if followed in full. We did, however, feel that not enough engagement had been carried out with the patients currently receiving these treatments.⁵

Following the decision, Healthwatch Hillingdon asked for measures to be put in place to support patients during the changes and we influenced the introduction of the 'Low back pain' information leaflet⁶ for patients.

² NHS North West London collaboration of CCGs - Brent, Central London (Kensington and Chelsea), Ealing, Hammersmith and Fulham, Harrow, Hillingdon, Hounslow, and West London (Westminster).

³ <https://www.hillingdonccg.nhs.uk/individual-funding-requests->

⁴ <https://www.nice.org.uk/guidance/ng59>

⁵ This excluded patients receiving Cervical Thoracic spinal injections as we agreed with the Policy Development Group that this was a very small number of patients that would be hard to identify.

⁶ <https://www.hounslowccg.nhs.uk/media/104721/3-ML4205-A5-6pp-Lower-Back-Pain-Booklet-Rev-4pp-Rev11.pdf>

In June 2018, The Hillingdon Hospitals NHS Foundation Trust sent a letter to all patients affected by the implementation of the Low Back Pain Policies (Appendices 3 and 4).

Number of letters sent

Outcome of Review	Number of Patients	Reasons
Discharged to GP	158	Discharge letters were sent to both the GP and the patient indicating the reason for removal from the waiting list. Recommendations were made to the GP on how to manage this group of patients.
Booked for an Outpatients appointment	48	Letters were sent to these patients as they were removed from the waiting list because they did not meet the new criteria. However, upon review of these cases additional letters were sent to these patients to discuss alternative treatment that could be offered that met the new criteria.
Booked for another procedure	109	These patients were not removed from the system as they met the new policy criteria. Hence no discharge letters were sent to these patients.
PPwT criteria or procedure not covered by PPwT	178	These patients were not removed from the system as they met the new policy criteria. Hence no discharge letters were sent to these patients.
Acupuncture	786 (70 moved to an Outpatients appointment)	All patients were sent letters explaining why acupuncture was decommissioned. These were also copied to the GP. 70 patients were given outpatient appointments as alternative treatment was available in line with the new criteria.

Healthwatch Hillingdon's contact details were included in the letter, at the request of the Hillingdon Clinical Commissioning Group (CCG), to provide information and support to patients affected by the changes.

We were subsequently contacted by 40 individuals who had received a letter from The Trust. We explained the decision that had been taken and the reasons behind the letter that people had received. We gave them an opportunity to talk to someone about their concerns and anxieties, answered their questions, gave them options, and gathered their feedback (see Appendix 5).

The people we spoke to reported that they were shocked and confused to receive the letter. They thought that there was a lack of information as well as a lack of support for them. Patients wanted to know why they hadn't been told of the decision much earlier, and felt that they had been left without treatment for their condition.

None of the patients we had contact with had received the leaflet on managing lower back pain with their letter, which was unfortunate as the leaflet gave information and alternative ways of coping with back pain.

“I have received a letter telling me that the pain service clinics have been withdrawn. I've been having acupuncture for three years. The letter says I should go back to my GP, but the GP is not a specialist in chronic pain and feel I have been let down. I did not receive any booklet giving further advice, just a letter.”

As patients had been discharged to primary care, we referred them back to their GP to seek further advice and treatment. For those who wished to complain about the commissioning decision taken to stop their treatment, we advised individuals to contact the Brent, Harrow, and Hillingdon Clinical Commissioning Groups complaints department.

We then contacted 21 patients around a month after they had received their letter, to follow up with them. Patients reported that the contact they'd had with NHS organisations, and the response from NHS professionals, had not eased their anger or confusion.

At the time of contact, only one patient was actively receiving treatment. The remainder were either waiting for future treatment to happen or had been told there was no alternative treatment. None of the patients were told about Individual Funding Requests by the NHS.

“My GP told me it would be pointless for me to try and complain or to pursue the matter as NICE have recommended this course of action and the decision is finite.”

Patients felt that the response from the hospital was unsupportive. We were told that individuals had tried to contact the pain clinic but could not get through on the telephone. They also said they had contacted the hospital's Patient Advice and Liaison Service (PALS), which requested information from the pain clinic, but at the time of our contact patients had not received any information.

Patients who contacted the Hillingdon Clinical Commissioning Groups complaints department said they'd had an indifferent response, and were not given answers about treatment, being told that the hospital would contact them or that they should go and see their GP.

Following our findings, we made several recommendations for commissioners and service providers to consider in regard to future policy implementation. The full findings can be read in the main body of this report. Conclusions can be found on page 14 and recommendations on page 18.

Context

Lower Back Pain Procedures are one of 47 procedures in North West London which have set clinical criteria that must be reached before treatment is funded. These are known as Planned Procedures with a limited Threshold (PPwTs).

It is the responsibility of GPs and hospital doctors to ensure that only patients meeting the defined criteria are referred or treated. Under exceptional circumstances, GPs can submit a request to the Clinical Commissioning Group for patients that do not meet the threshold criteria. This is known as an Individual Funding Request.

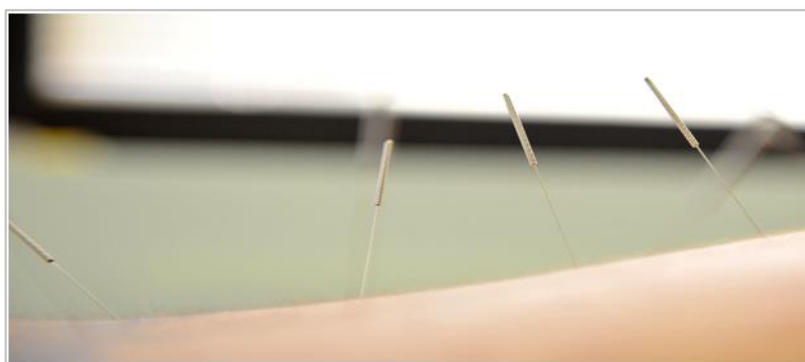
The eight North West London Clinical Commissioning Groups work together to manage their Planned Procedures with a limited Threshold and Individual Funding Requests.⁷

The eight Clinical Commissioning Groups are individually responsible in law for the commissioning decisions they take, but they work together to reduce inequality by ensuring the same policies apply for all 2.2 million GP registered patients across North West London.

To help achieve this, the NHS North West London Collaboration of Clinical Commissioning Groups have established a joint Policy Development Group to determine which procedures have limited thresholds and agree the clinical criteria policy for each of these PPwTs. The Policy Development Group is made up of a varied range of clinicians, professionals, and lay members, with diverse backgrounds and expertise. Healthwatch are a non-voting member in attendance.

Following updated guidance published by the National Institute for Clinical Excellence (NICE)⁸ in 2016, the Policy Development Group reviewed the treatment of Low Back Pain and developed new policies for the management of low back pain. The Acupuncture Policy and the Low Back Pain and Sciatica Policy were aligned with the NICE guidelines and informed by the feedback taken from the North West London Clinical Commissioning Groups clinical workshop and a patient forum.

The February 2017 workshop included pain management clinicians, orthopaedic surgeons, physiotherapists, community providers, commissioners, and lay members (patient representatives). The forum was held to



⁷ <https://www.hillingdonccg.nhs.uk/individual-funding-requests->

⁸ <https://www.nice.org.uk/about>

provide patient feedback on the proposed pathway and was attended by 10 patients/carers.

The recommendations made by the Policy Development Group for the management of low back pain were presented at the North West London Clinical Commissioning Groups' Collaboration Board (now Joint Committee) in October 2017.

The Collaboration Board collectively approved the implementation of the policies and they were adopted on 1st April 2018.

As a member of the Policy Development Group, it is well documented that Healthwatch Hillingdon have continued to recommend that public consultation is carried out prior to any changes to policy and that the views of those people directly impacted by any proposed change should be sought and heard.

Healthwatch Hillingdon were present throughout the period the management of low back pain policies were being developed. We recognised that the NICE lower back pain guidance was evidence based and reasonable, if followed in full. We did however feel that not enough engagement had been carried out with the patients currently receiving these treatments⁹; to understand their views, how these changes would affect them and what support they might need if the changes were implemented.

Following the commissioning decision taken to adopt the recommended policies in North West London, Healthwatch Hillingdon asked for measures to be put in place to support patients during the changes and influenced the introduction of the information leaflet for patients. The leaflet was approved by the North West London Lay Partners Group before publication and assurances were given that every patient affected by the changes would be provided with support and given a copy of the 'Low back pain' leaflet¹⁰.

Methodology

In June 2018, Healthwatch Hillingdon agreed to the Hillingdon Clinical Commissioning Group's request for our contact details to be included on the letter The Hillingdon Hospitals NHS Foundation Trust were sending to all patients affected by the implementation of the Low Back Pain Policies.

The Hillingdon Hospitals NHS Foundation Trust sent letters to patients in two stages. The first to acupuncture patients (Appendix 3) and the second to those receiving other lower back pain treatments (Appendix 4).

When contacted by patients who had received a letter, or their carer/family member, we:

- Provided information and advice
- Recorded feedback

⁹ This excluded patients receiving Cervical Thoracic spinal injections as we agreed with the Policy Development Group that this was a very small number of patients that would be hard to identify.

¹⁰ <https://www.hounslowccg.nhs.uk/media/104721/3-ML4205-A5-6pp-Lower-Back-Pain-Booklet-Rev-4pp-Rev11.pdf>

- Asked people if they were happy for us to contact them in a month to check on their progress
- Contacted patients with follow up calls and recorded the update on how they were being supported.

Our Findings

STAGE 1 - Initial Contact:

Confusion

Patients told us they didn't know what to do, they were unclear on who was responsible for taking the decision to stop providing these procedures, who they should contact and what they were supposed to do to manage their pain going forwards.

- The letter that was sent out to patients was addressed from The Hillingdon Hospitals Trust, therefore some people told us they thought it was the hospital itself, not the Clinical Commissioning Group, who was responsible for the changes.
- People did not know of the Clinical Commissioning Group.
- Many patients stated that they felt 'left in the dark' about what other options for treatment might be available.
- This lack of understanding and worry about their health going forwards led to many people saying they were suffering from stress and distress, even being "frightened".
- Several said the procedure they had been having was the only thing that had worked for them and their only hope of pain relief.

- *"As I'm on the waiting list for surgery I worry that I'll have to wait another year for this at least, and that now I won't have anything to help with the pain. No care plan has been put in place, I feel I have just been left without anything."*

- *"The injections have a life changing affect to my mobility, so much so that they are the difference between me being house bound or not so."*

- Some patients expressed confusion over the fact that they had been sent a letter telling them the service they had been receiving had ceased from April - but they had already undergone treatments after this date.

- Others said they would have preferred not to have been started on treatment.
- Others had been on the waiting list for an initial appointment for a long time, only to then be told the service was being cancelled.

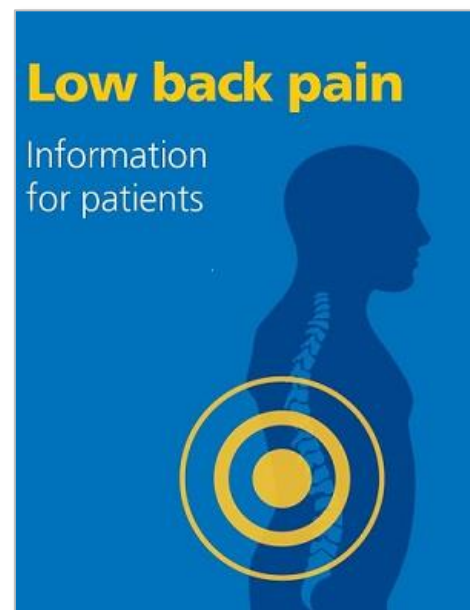
Lack of information

The overwhelming reaction to receiving a letter about the withdrawal of these services was the sense of the abrupt cut off, with patients telling us the letter came “out of the blue”.

- Every person who contacted us expressed the same feeling - they had been left without any alternative to manage their pain and had no idea what to do next, with one person even going so far as to tell us that the pain management treatment they had been receiving had been helping them ‘to live’.

• *“The letter states that the hospital will be in touch with patients to discuss other options - but nothing has happened.”*

- None of the people we spoke to had received the booklet (right) on managing pain that was supposed to accompany the letter sent out to them.
- “I’m staggered that the NHS can be so clinical and abrupt with the cessation of my treatment. This decision came like a bombshell.”
- Another point people raised was that they wanted to complain but were unsure who/where to complain to. We were able to signpost people to the Brent Harrow and Hillingdon Clinical Commissioning Groups’ complaints department.



Lack of support

Many people who contacted us told us they felt “let down” by the NHS.

- “I would have thought that Hillingdon Hospital would have seen me and given some alternative, not just sent me back to my GP.”
- “I find this very abrupt - there is no advice on what to do next, or any kind of counselling to help with this change. I would have liked the opportunity to be able to talk to the nurse who was doing the acupuncture, to get further advice on where else I could go. I feel it is wrong to withdraw funding for this service.”

- “No care plan has been put in place, I feel I have just been left without anything to help me or my pain.”
- “I’ve paid into the NHS since I was 15 and the injections really helped me. Surely injections are cheaper than having to have surgery? The letter states that the hospital will be in touch with patients to discuss other options - but nothing has happened.”

● *“I suffer from arthritis in my spine and have been having acupuncture - without this I would have been in a wheelchair. Acupuncture was a big thing for me as it allowed me to work and carry on a normal life. Now I’ve had a letter cancelling all further treatment with acupuncture. I can’t function without this. I am ‘eating’ painkillers again - what can I do now?”*

- Patients felt they hadn’t been given any help with this situation from the health professionals and one even said they were “disgusted”, but thanked HWH for listening and are glad we are trying to do something to represent patients’ views.

Confusion over the decision

The overriding response from people who contacted us was one of disappointment, confusion and disagreement with the withdrawal of these services with one individual arguing: “I thought the hospital aim was to STOP pain? This decision seems to be about saving money!”

- However, one respondent said that whilst they understood and agreed with the NICE guidelines, they did feel that a “blanket approach” was not helpful: “I feel that each patient should be dealt with case by case as treatment may work for some people.”
- Respondents were also annoyed that the service is still being provided in Hillingdon Hospitals to patients who live outside of North West London: “My GP didn’t know anything about this change and I haven’t received any letter. However, the hospital told me that people who live in Bucks can still get the treatment at Hillingdon! I feel that people’s treatment shouldn’t just be cut off. There has been no information or continuity of what is happening.”
- Another individual expressed their feeling that if you have been referred by a GP to the pain clinic, it is because you cannot cope with the pain you are experiencing. They said they were “distracted” at receiving the letter informing them of these changes.

STAGE 2 - Follow Up Contact:

GP Response

After following up with people we had initially contacted, it became evident from our research that there were a number of GPs unaware of the changes. Although an isolated incident, Healthwatch Hillingdon received one email from a GP surgery asking us what they should advise their patients.

- People reported having difficulties in even being able to make an appointment to see a doctor, many stated that it was not helpful to receive a letter that just sent them back to their GP.
- Our respondents told us that their GP had said there was nothing else they could do for them - they were not even offered a referral back to the pain clinic.
- “My GP told me it would be pointless for me to try and complain or to pursue the matter as NICE have recommended this course of action and the decision is finite.”
- Some patients were referred to physiotherapy or the pain clinic. With two patients being offered the decommissioned service with other providers.
- Only one person was actively having treatment. They did however say that their physiotherapy was working for them.
- None of our respondents were advised of the Individual Funding Request by their GP, although a patient was going down this route after asking about it through our advice.

Clinical Commissioning Group Complaints Response

Patients who contacted the clinical commissioning group complaints department were not satisfied with the pace or content of responses. One person told us they called the Clinical Commissioning Group complaints number but were told by them to go back to their GP.

- Another was informed that they would be sent a consent form and the Clinical Commissioning Group would then investigate their complaint - but they were still waiting at the time we contacted them.
- Two others rang the complaints department and left a message but had not received any call back. One person advised that they had received a voicemail when out but had not yet made contact.
- “The Hillingdon Clinical Commissioning Group shared on their Twitter Feed a link to the Ealing Clinical Commissioning Group advising of a 'Change of policy: cervical and thoracic facet joint injections' which stated that all people on the waiting list would be informed. I replied to the Twitter Feed asking when people would be informed but did not receive a response. I just

wanted to feedback that I think that it is a poor show, for people who are experiencing pain and think that they will be getting pain relieving injections, not be informed in a timely manner that this is not the case.”

- In response one person received a letter saying the hospital will contact them and they hadn't.

Hospital Response

People told us they felt they got no help from the hospital, particularly when receiving the letter that stated: “Our staff have reviewed your medical notes and unfortunately our hospitals do not currently provide any alternative treatment for your condition” It left them feeling unsupported and without any help or information.

- Patients were confused that they were informed they were being discharged from these pain management services but had received appointment letters to attend the hospital after the April policy change. Several phoned us to ask whether they should still attend or not.
- Those who tried to contact the hospital themselves fared no better: “I tried to contact the Pain Clinic for an update and as I was unable to get through, then contacted PALS. I have been advised by PALS that they have passed on my two queries to the Pain Clinic, but I have still had no response.
- There was also confusion surrounding patients reporting that they had had one type of injection cancelled but were then booked in for a different type of injection.
- One individual told us how they feel that, having paid into the system all their life, the NHS has let them down badly. They have had to resort to going private to get their injection.

Patient Story

I went back to my GP but was told there was nothing the GP could do. I feel that, having paid into the system all my life, the NHS has let them down badly.

All I wanted was this one injection, which worked for me.

I suffered this excruciating pain from 2009 and the cause was from my job as a carer lifting patients and pushing heavy wheelchairs.

I attended my GP from 2009 who prescribed strong painkillers.

The doctor finally referred me to Mount Vernon in June 2013, where I saw a pain consultant. He advised me to go back to my GP, swim, and exercise. He recommended my GP arrange for me to have physio.

In August 2013 I commenced a course of six physio sessions, which didn't help at all.

After the physio I saw the pain consultant again early 2014 and he arranged for an MRI scan which revealed nerve endings were pressing on vertebrae and recommended a lumbar epidural steroid injection, which I had in July 2014.

This helped me to manage the pain along with painkillers. I had the second injection one year later in July 2015. A third injection in July 2016 and a fourth injection July 2017

The fifth injection was due July 2018, but I received a letter dated on 4th August 2018 informing me the procedure is withdrawn.

The pain I suffer is unbearable and I decided to borrow the money from my sister and have the procedure done privately. I am paying her back at £50.00 per month.

The procedure cost £1371. Which will take me over two years to pay back.

The first I knew of the withdrawal of this procedure was from the letter I received on 8th August 2018. Why was I never consulted about the procedure being withdrawn?

I was born in London and my grandparents, parents, my brothers and sisters, husband and children have all paid into the NHS, some since it began, so can you please explain to me why I was not allowed this procedure via the NHS.

Conclusions

The evidence outlined in this report clearly shows that patients, their families, and friends have not experienced a good implementation of the low back pain policies in Hillingdon.

Although the focus of the feedback from patients was on the local process to implement change, our research shows that there is important learning to be taken from the whole decommissioning process.

Although the eight NWL Clinical Commissioning Groups made the decision to adopt the new policies for back pain collectively, implementations and communication strategies have varied in effectiveness.

For Healthwatch Hillingdon it raises a question about the wider Clinical Commissioning Group, as a constituted body, when it makes decisions jointly, or collaboratively, with the other seven Clinical Commissioning Groups in North West London, and how they can work together to effectively implement changes through agreed communication strategies.

Our considerations, the points of learning we raise and the recommendations we make, are based on comparing the information provided to us by patients with published NHS England guidance and current law.

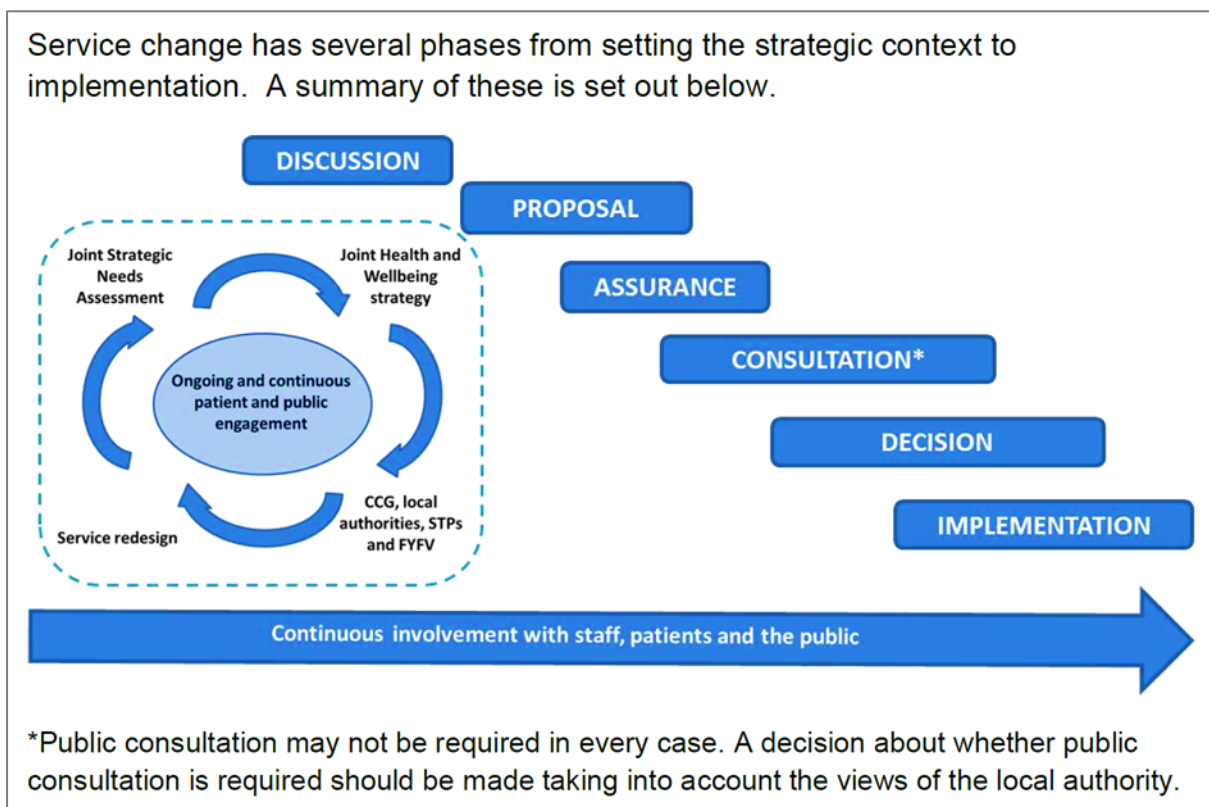
Engagement in Service Change

NHS England published guidance ‘Planning, assuring, and delivering service change for patients’¹¹ (updated in March 2018) outlines good practice for commissioners on the NHS England assurance process for service changes and reconfiguration.

As the guidance states:

there is no legal definition of service change but broadly it encompasses any change to the provision of NHS services which involves a shift in the way front line health services are delivered, usually involving a change to the range of services available and/or the geographical location from which services are delivered

It is Healthwatch Hillingdon’s opinion that the decommissioning of both acupuncture and lower back pain constitutes a change in service and therefore consideration should be given to all phases of the outlined process.



¹¹ <https://www.england.nhs.uk/wp-content/uploads/2018/03/planning-assuring-delivering-service-change-v6-1.pdf>

Healthwatch Hillingdon would agree that to a point these phases have been followed in the decommissioning process. It is not until we come to the stage of consultation (engagement) that we feel the required processes have not been followed thoroughly.

Engagement of patients and carers in the process of service change is absolutely key. It may not mean that a decision will be overturned but it does enable questions to be adequately answered in the decommissioning communications, which may clarify confusion and alleviate anxiety. This needs to be taken into account in future decommissioning processes, particularly those at NWL level where there may be a perceived or actual risk that decision-making is removed from a local level.

It is Healthwatch Hillingdon's view that before deciding whether to adopt a recommendation made by the Policy Development Group, that Hillingdon Clinical Commissioning Group should carry out further engagement with Hillingdon residents who are directly impacted by proposed changes to PPwT policies.

We believe that, as outlined in NHS England guidance,¹² the Hillingdon Clinical Commissioning Group have a legal duty to engage these patients, under Section 14Z2 2b of the National Health Service Act 2006 (as amended by the Health and Social Care Act 2012):

(2) The Clinical Commissioning Group must make arrangements to secure that individuals to whom the services are being or may be provided are involved (whether by being consulted or provided with information or in other ways) -

(b) in the development and consideration of proposals by the Clinical Commissioning Group for changes in the commissioning arrangements where the implementation of the proposals would have an impact on the manner in which the services are delivered to the individuals or the range of health services available to them and ...

This is also reflected in the Hillingdon Clinical Commissioning Group Constitution 2018 - APPENDIX J 'Statement of Principles in relation to Patient and Public Involvement'¹³

Healthwatch Hillingdon believes that the Hillingdon Clinical Commissioning Group made the decision to adopt the recommendations of the Policy Development Group without sufficient local engagement.

In some cases public consultation is not required in the case of service change, but the decision as to whether it is applicable should always be taken in consideration with the local authority Health and Wellbeing Boards and Health Scrutiny, under Section 244 of the NHS Act 2006, which in this case did not happen.

¹² <https://www.england.nhs.uk/wp-content/uploads/2017/05/patient-and-public-participation-guidance.pdf>

¹³ <https://www.hillingdonccg.nhs.uk/download.cfm?doc=docm93jjjm4n3401.pdf&ver=6998>

Having already seen the negative effect on other service delivery within Hillingdon of procurement carried out in isolation, Healthwatch Hillingdon would like to see all potential service change discussed at the Health and Wellbeing Board at the earliest opportunity.

Healthwatch Hillingdon has always held the Hillingdon Clinical Commissioning Group's engagement through service change in high regard. In instances where decisions are made collectively by the NWL Clinical Commissioning Group, collaborative, robust, locally focussed plans for engagement and implementation are essential.

The confusion and anxiety experienced by the patients we spoke to may have been significantly reduced by early dissemination of information and a timely programme of review and consultation regarding their ongoing options for care. In addition, there was variable understanding and awareness amongst GPs both of the decision that had been taken and the implications for planning the future care of their patients.

Implementation

It is our understanding that, as required under Section GC13 of The NHS Standard Contract 2017/18 and 2018/19¹⁴, the Hillingdon Clinical Commissioning Group gave The Hillingdon Hospitals NHS Foundation Trust six months' notice of its intention to decommission these services for Hillingdon residents.

Healthwatch Hillingdon do not know what happened from this point in the process until the point the letters were to be sent out. Evidence however, as we have seen, strongly suggests that in the course of implementing the decision, the process between Hillingdon Clinical Commissioning Group and The Hillingdon Hospitals NHS Foundation Trust, has not worked in the way that it should have to reduce anxiety and offer a more supportive way forward. It has been confirmed to us that due to operational oversights, time was lost.

As Healthwatch Hillingdon are not in receipt of the full facts we will not speculate as to why this happened.

From the evidence we have collected, it appears that during the 6 months' notice period, that there was no implementation plan in place at The Hillingdon Hospitals NHS Foundation Trust. Or if there was, it was not being actioned.

The evidence clearly demonstrates that informing a patient at the end of the six months that the procedure they are having is immediately unavailable, is not the way to support a patient through service change. Especially when it is by a letter that could have been constructed in a more supportive way.

¹⁴ <https://www.england.nhs.uk/wp-content/uploads/2018/05/3-nhs-standard-contract-2017-19-particulars-general-conditions-may-2018.pdf>

Nor is a blanket approach of discharging patients back to their GP without discharge planning.

The upset and distress that patients have told us they have suffered could have been avoided.

Healthwatch Hillingdon would have expected early information to go to patients on the changes and a planned programme, where patients were reviewed, and their distress managed.

Patients should have had an opportunity to be involved; and:

- influence how their care in Hillingdon was delivered
- be prepared and supported through the change process
- have conversations about their future care and the alternative treatments that could be offered
- consideration be taken on whether their treatment could continue through an individual funding request.

Healthwatch Hillingdon would have also expected general practice to be prepared for the implementation.

When we saw a letter sent to the GPs, dated 28 June 2018, informing them of the hospital's decision to blanket discharge patients, it certainly did not inspire us when we saw it started 'You may remember that last year, North West London CCGs revised their policy for low back pain and sciatica'.

This did not give Healthwatch Hillingdon the confidence that GPs were in a planned position to support patients. With many GPs not aware of the changes, or their implication, and some seemingly ill-prepared to offer alternative treatment, evidence would suggest that we may have been right.

After the decision was made in 2017, Healthwatch Hillingdon were hesitant that patients would be supported. In Hillingdon, this has become a reality. Typified by the fact that not one of the patients we spoke to received the patient leaflet specially designed to support them.

Recommendations

Healthwatch Hillingdon recognises, along with its partners, that this decommissioning project could have been delivered to a much higher standard. Therefore, we recommend the following:

1. A review of the implementation process in order to learn lessons and produce a framework for delivering change in the future.

2. That out of the review comes a process for adopting and implementing Policy and Development Group recommendations ensuring that there is a clear and consistent approach to policy implementation. This should include engagement with the affected patients and stakeholders. Additionally, robust communication and implementation plans that identify clear roles and responsibilities of commissioners and providers at both NWL and CCG level should be part of this process.
3. The findings of this review be reported to the Health and Wellbeing Board and the External Services Scrutiny Committee.
4. This new process is published to an agreed target date.
5. When informing patients and the public of service change in Hillingdon, that Healthwatch Hillingdon details are always added to the information sent, to ensure patients can be independently supported.

Appendices

Appendix 1: Acupuncture Policy

<https://www.hounslowccg.nhs.uk/media/104742/Acupuncture-v41.PDF>

Acupuncture

Policy

NWL CCGs **do not** commission acupuncture for any indication due to its lack of clinical effectiveness. Funding may be considered through the Individual Funding Request (IFR) route in exceptional clinical circumstances.

These policies have been approved by the eight Clinical Commissioning Groups in North West London (NHS Brent CCG, NHS Central London CCG, NHS Ealing CCG, NHS Hammersmith and Fulham CCG, NHS Harrow CCG, NHS Hillingdon CCG, NHS Hounslow CCG and NHS West London CCG).

References

NICE Clinical Guidelines

- <https://www.nice.org.uk/guidance/ng59>

Cochrane Evidence

- <http://uk.cochrane.org/>

Latest version of the policy is available at:

<http://www.hounslowccg.nhs.uk/what-we-do/individual-funding-requests.aspx>

Version 4.1 (July 2017)

Low Back Pain and Sciatica Policy

Policy

1. **NWL CCGs do NOT commission the following for low back pain and non-radicular spinal pain:**
 - a. Facet joint injections
 - b. Therapeutic medial branch blocks
 - c. Intradiscal therapy
 - d. Prolotherapy
 - e. Trigger point injections with any agent, including botulinum toxin
 - f. Epidural steroid injections for chronic low back pain or for neurogenic claudication in Patients with central spinal canal stenosis
 - g. Any other spinal injections not specifically covered above
2. **NWL CCGs fund epidurals (local anaesthetic and steroid) only in patients who have less than three months history of acute and severe lumbar radiculopathy at time of referral.**
3. **NWL CCGs will NOT fund Spinal fusion or lumbar disc replacement for low back pain. Surgical procedures for specific causes of LBP e.g. spondylolisthesis, scoliosis or Structural disease are routinely funded where clinical indicated.**
4. **NWL CCGs recommend that imaging should not routinely be offered in a non-specialist setting for people with low back pain with or without sciatica.**

Funding may be considered through the Individual Funding Request Route (IFR) in exceptional clinical circumstances.

Please note that there are dedicated policies for Acupuncture and Radiofrequency Denervation.

These policies have been approved by the eight Clinical Commissioning Groups in North West London (NHS Brent CCG, NHS Central London CCG, NHS Ealing CCG, NHS Hammersmith and Fulham CCG, NHS Harrow CCG, NHS Hillingdon CCG, NHS Hounslow CCG and NHS West London CCG).

References

NICE Clinical Guidelines

- <https://www.nice.org.uk/guidance/ng59>

Latest version of the policy is available at:

<http://www.hounslowccg.nhs.uk/what-we-do/individual-funding-requests.aspx>

Version 4.1 (July 2017)

Appendix 3: Letter sent to acupuncture patients



Hillingdon Hospital
Pield Heath Road
Uxbridge
Middlesex
UB8 3NN

«Title» «FirstName» «LastName»
«JobTitle»
«Company»
«Address_1»

25 June 2018

Dear **Patient name**

Changes to Hillingdon pain services which affect your acupuncture treatment

We are very sorry to have to inform you that our hospital trust is no longer able to provide any acupuncture treatments. Unfortunately this means that we have had to cancel the procedure you were expecting to have.

This is because from 1 April 2018 the North West London Care Commissioning Group (CCG) - which includes Hillingdon - has decommissioned a number of pain procedures including all acupuncture treatments. This means that funding is no longer provided for them.

They have taken this decision following new guidance issued by the National Institute for Clinical Excellence (NICE); the body that provides guidance and advice regarding appropriateness of health and social care.

Following this change our Trust is stopping delivering acupuncture services in June. Our staff have reviewed your medical notes and unfortunately our hospitals do not currently provide any alternative treatment for your condition.

Switchboard: 01895 238282 Main Fax No: 01895 811687



The Hillingdon Hospitals NHS Foundation Trust - Chair Richard Sumray

We understand that you will be concerned about this change to your treatment plan and we recommend that you contact your local GP surgery to discuss the ongoing care options with your GP.

Your GP has been informed by the CCG that these procedures are no longer available on the NHS. We have also informed your GP that your care has been transferred back to their practice.

More information about this change, including the NICE guidance, is available by visiting: <http://www.hillingdonccg.nhs.uk/latest-news/new-low-back-pain-and-sciatica-policy-for-northwest-london-3130/> and <http://www.nice.org.uk/guidance/ng59>

Your GP may also be able to provide more information.

Please accept our sincerest apologies for the disappointment and inconvenience caused by this news.

Yours sincerely

Chronic Pain Services Management

If you would like to talk to an independent person about these changes you can contact: **Healthwatch Hillingdon**

Tel: [01895 272997](tel:01895272997)

Email: office@healthwatchhillingdon.org.uk

Write: Healthwatch Hillingdon, 20 Chequers Square, The Pavilions Shopping Centre, Uxbridge, UB8 1LN.

Healthwatch Hillingdon is your local watchdog for health and social care. They monitor services in the borough and make sure that resident's views and experiences of services are gathered and heard.

Appendix 4: Letter sent to spinal injection patients



Hillingdon Hospital
Field Heath Road
Uxbridge
Middlesex
UB8 3NN

«Title» «FirstName» «LastName»
«JobTitle»
«Company»
«Address_1»

25 June 2018

Dear **Patient name**

Changes to pain services in Hillingdon which affect your planned treatment

We are very sorry to have to inform you that our hospital trust is no longer able to provide a number of procedures for the treatment of lower back pain. Unfortunately this means that we have had to cancel the procedure you were expecting to have.

This is because from 1 April 2018 the North West London Care Commissioning Group (CCG) - which includes Hillingdon - has decommissioned the procedures listed below. This means that funding is no longer provided for them.

They have taken this decision following new guidance for best practice in the management of lower back pain issued by the National Institute for Clinical Excellence (NICE); the body that provides guidance and advice regarding appropriateness of health and social care.

Following this change our Trust is stopping delivering these services in June. Our staff have reviewed your medical notes and unfortunately our hospitals do not currently provide any alternative treatment for your condition.

We understand that you will be concerned about this change to your treatment plan and we recommend that you contact your local GP surgery to discuss the ongoing care options with your GP.

The procedures affected by the change are:

- Facet joint injections
- Therapeutic medial branch blocks

Switchboard: 01895 238282 Main Fax No: 01895 811687



The Hillingdon Hospitals NHS Foundation Trust - Chair Richard Sumray

- Intradiscal therapy
- Prolotherapy
- Trigger point injections
- Epidural steroid injections Any other spinal injection
- Acupuncture

Your GP has been informed by the CCG that these procedures are no longer available on the NHS. We have also informed your GP that your care has been transferred back to their practice.

More information about this change, including the NICE guidance and advice on managing low back pain, is available by visiting:
<http://www.hillingdonccg.nhs.uk/latest-news/new-low-backpain-and-sciatica-policy-for-north-west-london-3130/> Your GP may also be able to provide more information.

Although you may already be aware of the advice for managing back pain, a copy of the guidance has been enclosed for your information.

Please accept our sincerest apologies for the disappointment and inconvenience caused by this news.

Yours sincerely

Chronic Pain Services Management

If you would like to talk to an independent person about these changes you can contact: **Healthwatch Hillingdon**

Tel: [01895 272997](tel:01895272997)

Email: office@healthwatchhillington.org.uk

Write: Healthwatch Hillingdon, 20 Chequers Square, The Pavilions Shopping Centre, Uxbridge, UB8 1LN.

Healthwatch Hillingdon is your local watchdog for health and social care. They monitor services in the borough and make sure that resident's views and experiences of services are gathered and heard.

Appendix 5: Feedback logged on HWH CRM database:

Withdrawal of acupuncture service

2nd July 2018

Caller expressed how they would have preferred it if their treatment had not been stopped midway through, perhaps even should not have been started at all knowing that the service was going to finish before the end of treatment. Patient had found the treatment helpful for disc mis-alignment in neck. Had two sessions and was feeling the benefit.

We spoke to the caller and advised them to contact their GP for support/treatment options.

4th July 2018

I have just received a letter informing me that my acupuncture treatment has been withdrawn. I am not happy because I suffer a lot of pain through sciatica. What do I do now? I want to know how to complain, because I was half way through my treatment.

Alison explained to caller why our name was on the letter and advised caller to go back to their GP (Belmont Medical Centre) to ask how the GP will now support them or suggest treatments for their pain. Caller gave permission for us to follow up with them in two to three weeks.

6th July 2018

I am halfway through a course of acupuncture treatment for a neck problem and have received a letter telling me that my treatment has been stopped due to a lack of funding. I am unhappy about this and would like to know where I can complain to?

11th July 2018

Individual called on behalf of his wife, who has received a letter telling her that the acupuncture service has been stopped due to funding. Her final treatment was due in September. She did not receive any booklet on alternative treatments with the letter. Wants to know what to do now...

Advised the caller that his wife should go back to their GP to see what they are offering in terms of alternative support.

11th July 2018

"My wife has been receiving acupuncture at the hospital and it helps relieve the pain in her back. We work, pay taxes and they expect my wife to walk around in pain. I am incensed and am not having it. Who do I complain to about stopping the care? I want to make sure she gets her acupuncture."

Healthwatch gave caller the details of BHH complaints. Advised to go to GP to look at alternative care. Noted that they did not receive any booklet about alternative treatment with the letter.

12th July 2018

I have received a letter telling me that the pain service clinics have been withdrawn. I've been having acupuncture for three years. The letter says I should go back to my GP, but the GP is not a specialist in chronic pain and feel I have been let down. I did not receive any booklet giving further advice, just a letter.

Explained Healthwatch's role and advised caller to see their GP for further support. Caller said they want to complain and asked for details of who to complain to.

13th July 2018

I broke my back two or three years ago and have been having acupuncture for pain relief every six weeks; it does help. I received a letter today telling me this service has been stopped. I find this very abrupt - there is no advice on what to do next, or any kind of counselling to help with this change. I would have liked the opportunity to be able to talk to the nurse who was doing the acupuncture, to get further advice on where else I could go. I feel it is wrong to withdraw funding for this service.

Explained Healthwatch's role and how we are gathering feedback. Advised caller to go to their GP to seek further support/treatment. Caller asked for details of Clinical Commissioning Group complaints.

19th July 2018

Last year I had five sessions of acupuncture and I had appointments booked in October and November. I found that acupuncture worked for me. Now I have received a letter telling me that the acupuncture service has been stopped due to lack of funding. I felt angry at first, now I feel let down. What can I do?

Advised caller to go back to GP to seek further support and treatment. Caller agreed to us following up with them to see what action GP has taken.

20th July 2018

I have received letters from The Hillingdon Hospitals cancelling my son's forthcoming acupuncture appointments and telling him to go back to his GP. I am not happy because he has suffered pain for three years. He had injections in his spine, but these did not work, and he was due to start acupuncture, but this has been cancelled. I would have thought that THH would have seen him and given some alternative, not just sent him back to his GP. How can I complain?

Gave details of BHH complaints and advised caller to go to GP to initiate new referral to the pain clinic.

24th July 2018

I received a phone call yesterday from the hospital, telling me that the acupuncture service has been withdrawn. I have been having acupuncture for over two years and am in severe pain. I have had physio in the past but that did not help me, in fact I feel that it made the problem in my neck worse. The hospital told me I should go to my MP about this, because I feel it is wrong to withdraw this service, and so suddenly.

Advised caller to make an appointment to see their GP for further support and treatment options. Caller agreed to be followed up by us in two to three weeks to see what the response was from their GP.

24th July 2018

I've been having acupuncture treatment for my back for a while now. The problem with my back is being investigated still, and the acupuncture helps relieve the pain and keeps me going. I've had a letter from the hospital telling me there is not going to be any more funding for this treatment. As I'm on the waiting list for surgery I worry that I'll have to wait another year for this at least, and that now I won't have anything to help with the pain. No care plan has been put in place, I feel I have just been left without anything.

Advised caller to make an appointment to see their GP for further support and to discuss treatment options. Caller is happy for us to follow up with them to see what the GP advised. They also said that they will see how this goes with the GP and then, if not happy, would ask us for the details of how to complain to the Clinical Commissioning Group.

20th August 2018

I suffer from arthritis in my spine and have been having acupuncture - without this I would have been in a wheelchair. Acupuncture worked and was a big thing for me as it allowed me to work and carry on a normal life. Now I have had a letter cancelling all further treatment with acupuncture. I can't function without this. I am 'eating' painkillers again. What can I do?

Advised caller to see their GP to see what other treatment options there are. Informed caller about making an Individual Funding Request.

23rd August 2018

I've been having acupuncture pain relief for the past two years. During my last appointment at THH they told me they would not be able to provide me with acupuncture anymore due to funding cuts. My GP didn't know anything about it and I haven't received any letter. However, the hospital told me that people who live in Bucks can still get the treatment at Hillingdon! I feel that people's treatment shouldn't just be cut off. There has been no information or continuity of what is happening.

Gave the caller the BHH Clinical Commissioning Group complaints department details to find out why they had not received a letter.

28th August 2018

Individual phoned about their mother receiving a letter to tell her that her acupuncture treatment has been stopped. The mum has been having acupuncture at THH for four years. On 17th July, the GP got a letter from the Pain Clinic to say that the mum needed to be re-referred as they can only give someone so many treatments. So, she was re-referred for August. But now she has had a letter saying all treatment is cancelled. Individual feels this has all been a waste of time and effort. They are also annoyed that the letter states that the service is still being provided to patients who live outside of north west London.

Advised caller to arrange an appointment for their mother with the GP, to ask for an individual funding request. Also gave complaints number for the BHH Clinical Commissioning Group.

17th September 2018

Individual was receiving acupuncture for back pain but then received a letter informing them of the cancellation of the service. They tried to see their GP but were told to email in to the surgery. They received an email reply saying nothing else could be done. They are not happy with this response and how it was dealt with. In addition, they have been recommended for a Vitamin D injection by their diabetic nurse, as their Vitamin D levels are low. The GP says this jab is not available at the surgery. The individual says they are unable to take tablets so need to have a jab. They also have autism but feel that the GP surgery does not make any allowance for this. They have a telephone consultation with the GP this week to discuss the Vitamin D situation.

Informed the individual about making an individual funding request for acupuncture; and asking the GP to send them back to the Pain Clinic. Gave them POhWER details for help with making a complaint regarding the issues they have raised about not getting adequate support with autism. As they have a phone consultation this week with the GP, advised them to ask the GP to follow up on the recommendation by the diabetic nurse that he has a Vit D jab, and to get an explanation if the GP refuses this.

Withdrawal of pain injections

3rd July 2018

I would like to let you know that this week I found out from a Hillingdon hospital pain clinic nurse that I have been taken off from the pain clinic as my GP has stopped funding for me. This has caused me a lot of stress and I'm now very concerned for my health. This is the ONLY clinic which had been helping me for the last 13-14 years. I have many health issues and over these past years the only place I felt I could rely and depend on for help and relief was the pain clinic at Hillingdon Hospital. Whenever I go to my GP for any health problem, his answer

has always been that I am under Dr XX in the pain clinic and he will help me with pain relief as they can't do anything further for me. Frankly speaking I find it useless visiting my GP surgery as they don't help me when I go to them with a health concern. I've always had to fight for help and with someone who has many existing health issues, the additional stress isn't needed. The one place I was assured will help and would take my pain seriously was this pain clinic.

Just recently in October 2017 I had TIA and the next day my left arm stopped moving and shoulder was severely painful. It took me five months to convince my GP to check my arm after various visits. In between, luckily, I had an appointment with the pain consultant, who helped me with strong pain killers and eventually he gave me an injection in my shoulder under general anaesthetic which has helped me quite a bit. He has always helped me on various times over the years when my own GP wasn't very bothered to help. I generally see him once in six months but have never been disappointed. I suffer with coccyx pain, even after removed in 2004 and after nerve trap it caused lots of issues in my left leg. I suffer with planter fasciitis in both my feet however my right foot is worse. I get flare ups quite often. Both shoulder tendons are torn. One shoulder had surgery but there was not much difference in pain and I was left with less mobility due to the surgery. I suffer with mild arthritis in spine, wrists, and fingers too. Being diabetic, all these health issues are truly a struggle for me. I walk with a walking stick and need two sticks when flare ups are worse. As mentioned, both shoulder tendons being torn is making life so difficult when I must use two walking sticks. The one place where I know I would get help, relief, and support from is the PAIN CLINIC Dr XX.

I would humbly like to request for you to not stop funding the pain clinic for me as this is my only hope and relief from pain I get.

10th July 2018

I had two pain relief injections in my spine last November and was waiting to have more but have now received a letter telling me that the funding has ceased for this service. I went back to my GP practice and was told by the GP that I could go to the hospital in Tooting in October, as this is the nearest hospital to offer the service - although there is no guarantee that when I get there, they will be able to give me the injection. I asked PALS at Hillingdon hospital what to do - they took my details two weeks ago but have not got back to me. I feel that I am still having problems in my back and am worried that I am developing another problem there.

Advised individual to go back to their GP to discuss the fact that they are experiencing new pain in their back and to ask for an examination.

7th August 2018

I have been supporting a lady who was referred to the Pain Clinic in September 2017 for a repeat injection to treat her back pain. Her GP chased this appointment on 2 occasions.

She was referred to H4All and I also tried to contact the Pain Clinic for an update and as I was unable to get through, then contacted PALS. I have been advised by PALS that they have passed on my 2 queries to the Pain Clinic on 9th July, but I have still had no response.

The Hillingdon Clinical Commissioning Group shared on their Twitter Feed a link to the Ealing Clinical Commissioning Group advising of a 'Change of policy: cervical and thoracic facet joint injections' (injections are no longer being commissioned) which stated that all people on the waiting list would be informed.

I replied to the Twitter Feed asking when people would be informed but did not receive a response.

I just wanted to feedback that I think that it is a poor show, for people who are experiencing pain and think that they will be getting pain relieving injections, not be informed in a timely manner that this is not the case.

8th August 2018

I need a steroid injection for lumbar pain. I take painkillers as well, but I find they don't work on their own and that I need the steroid injection. I've received a letter telling me that this service will no longer be available - I really feel this is not fair. These injections have helped me to live. What do I do now? Can I get them elsewhere?

Advised caller to make an appointment to see their GP to find out about alternative treatments/other options.

8th August 2018

Caller phoned to say that they have received a letter telling them that their planned steroid injection has been cancelled. They were very upset and want to appeal.

Gave caller the contact number for the BHH complaints department, as they stated that they wish to complain.

9th August 2018

I've had a letter telling me that I will no longer be able to have steroid injections. I think the decision is out of order. I've paid into the NHS since I was 15 and the injections really helped me. Surely injections are cheaper than having to have surgery? The letter states that the Clinical Commissioning Group/hospital will be in touch with patients to discuss other options - but nothing has happened. I would like to complain - the more people who complain, the better.

Advised caller to go back to their GP to seek alternative treatment options. Gave the caller the contact details for the Clinical Commissioning Group complaints department, as they wish to put in a complaint.

9th August 2018

My mother is 80 years old and has received a letter telling her that the steroid injection she was booked in for has been cancelled. She had had one before and it gave her pain relief for four to five years. She doesn't want to have any kind of surgery. Can we appeal this decision?

Advised caller to contact the BHH Clinical Commissioning Group regarding their request to appeal the decision.

12th August 2018

I had a steroid injection for back pain and sciatica. This did not work though, and now that the funding has been withdrawn anyway for injections, I just want to know what alternative options there are.

Caller has appointment with GP in two weeks and is happy for us to call them back for feedback following the visit.

12th August 2018

I am currently under the pain management clinic at Hillingdon Hospital. have waited for 27 months for steroid injections and have now received a letter telling me treatment has been withdrawn. I understand and agree with the NICE guidelines, but a blanket approach is not helpful. I feel that each patient should be dealt with case by case as treatment may work for some people.

Caller just wanted to have their say by giving us feedback.

13th August 2018

I've had a previous lumbar epidural steroid injection but have now received a letter telling me this has been discontinued. I am in discomfort and pain. What can I do?

Advised caller to go back to their GP and find out what alternative treatment is available. If unsatisfied, they can get back in touch with us.

13th August 2018

I was due to have a steroid injection on 23rd August, as I have a disc problem which traps my nerve. I am on anti-inflammatory medication. This was a trial to see if it would help me but now, I have received a letter telling me the injections have been cancelled. I thought the hospital aim was to stop pain? This decision seems to be about saving money! What do I do now?

Advised caller to go back to their GP to seek alternative options.

13th August 2018

I received a letter regarding the cancellation of my steroid injections. I've been having these injections over the past two years. What do I do now?

Advised caller to make an appointment to see their GP to see what alternative treatment options can be provided.

13th August 2018

I've been on the waiting list to have steroid injections but have now received a letter telling me that all steroid injections have been cancelled. What do I do now?

Advised caller to make an appointment to see their GP about alternative treatment options.

21st August 2018

I got a letter out of the blue telling me that my pain relief injections are no longer going to be provided. The facet joints have gone in my back and I had the nerves burnt. I went to see my GP and they say that nothing else can be done. This has frightened me. I must take regular pain relief and there are many thousands of people who also suffer back pain - the pain clinic has more people than the amount of appointments it can provide. So, I can't understand this decision. I have an appointment at Mount Vernon on 10th September, so I will still go to see the doctor there to see if she can do anything else.

Advised caller to still go to their September appointment and we will follow up with them after this to see what the consultant has advised.

22nd August 2018

I am calling about a letter sent to my mother, who is 93, about the cancellation of her steroid injection. This injection has worked for my mum - she really is in a lot of pain. I feel this has been very badly handled - there is no named person to complain to on the letter and it says they will be following up - but no-one has. How can I complain and what can I do about getting the pain relief she needs?

Gave the caller the details of the BHH complaints department. Also advised them to make an appointment for their mother to see her GP and ask about making an Individual Funding Request.

Follow Up Calls

16/08/2018

Phone call made to follow up with individual to see whether they got any help. Individual says they did not contact the CCG because, in the meantime, they received a call from the hospital telling them that the cancelled procedure (interfacet joint injection) has been replaced by another procedure (nerve blocking injection). Individual stated that it all seems a very silly system and that the whole process doesn't make sense and has been confused; and they feel that the original letter patients received has put patients through a lot of unnecessary turmoil.

16/08/2018

Contacted caller to follow up with them on their situation. They have asked the Chronic Pain Team for the use of a TENS machine but are still waiting for this. They had an appointment with this team in October, but this was cancelled, and they are now due to see them in March next year. They called the CCG complaints department and they told them to go back to their GP.

16/08/2018

Called individual to follow up with them. Their GP has said they can't do anything else for them other than prescribe painkillers. They have an appointment with the pain clinic on 23rd November but is in a lot of pain in the meantime. Caller told me: "I can't sleep at night. This is the only thing that makes me feel better. We should have been able to complete our treatment before they withdrew it completely. I feel we are not being given any help with our illnesses. It's not right that this just affects those receiving treatment in North West London."

16/08/2018

Contacted caller for update. They have been trying for the past three weeks to get an appointment with their GP (Harefield Practice). They have resorted to self-medication. They feel they haven't been given any help with this situation from the health professionals and said they are "disgusted" but thanked HWH for listening and are glad we are trying to do something to represent patients' views.

16/08/2018

Spoke to individual to follow up on their situation following cancellation of acupuncture treatment. They went back to their GP and was referred for physio, which they have been having on their shoulder the past three weeks and it seems to be working.

17/08/2018

Phoned individual to follow up on their situation. They rang the CCG complaints department but have not received any call back. So, they phoned the secretary of the pain consultant and were told that they are booked in to have a steroid injection in September. Previously, on 7th August, they received a letter telling them that their injection had been cancelled and recommending that they self-manage their pain through gentle exercise and physio. Individual was annoyed by this, saying that if you have been referred by a GP to the pain clinic, it is because you cannot cope with the pain you are experiencing. It transpires that her epidural injection has been cancelled and replaced with a steroid injection. She feels it has been very confusing and she was 'distracted'; at the first letter. She said that the CCG "don't care and don't think about the person concerned."

23/08/2018

Family member advised that they had written to CCG but awaiting a response.

To the Chronic Pain Services Management,

I am acting on behalf of my mother who recently received a letter informing her that her pain relief has been withdrawn. My mother is 93 years old and lives independently with minimal support but unfortunately has spinal stenosis and osteoporosis which causes severe back pain limiting her mobility. In the past, after the steroid injections she has been able stop oral analgesics for a considerable period therefore proving the treatment has a positive outcome and I am asking this treatment to be reinstated for her.

The letter I believe should have been accompanied by a leaflet, it was not, also information about any alternative treatments has not been forthcoming.

I would also like to point out my mother worked for the NHS for over 40 years as a registered nurse and feels now, in her time of need, it has let her down, putting her at risk of reduced mobility, increased pain, which in turn may cost the NHS more.

I do not think withdrawing treatment as a cost cutting exercise has had the required amount of information and back up for those concerned.

I look forward to your response.

Cc MP

Cc Healthwatch Hillingdon

03/09/2018

Spoke to individual, who said that the spinal consultant will write to their GP about trying another type of spinal injection. The individual had also contacted PALS at THH but had not heard anything back.

14/09/2018

Called individual to follow up. They went to their GP, but GP said there was nothing else they could do. Individual is going to put in a complaint to the CCG.

14/09/2018

Rang individual to follow up. they got in touch with their GP and they have been sent a letter to go back to the pain clinic at Hillingdon.

20/09/2018

Saw GP but nothing has happened. Feels very let down and pain is worsening. Knee problems and pain has increased and spread to toes. Feels cold. Suggested contacting BHH to make a complaint and telephone number of BHH given. Also advised go back to GP and make an Individual Funding Request. Happy for us to follow up again.

20/09/2018

Nothing has happened since seeing GP as was waiting for op to take place. Date for op was cancelled at last minute. Now needs to see GP again to be put back on list for op, has several other health issues and feels totally let down, in ongoing pain and in limbo. Advised perseveres with making appointment to see GP to find out what is happening with operation and ask GP to put in for an Individual Funding Request. Also gave details of BHH complaints department plus signposted to POhWER. Gave our number as needed. Would like to follow up.

20/09/2018

Went to see GP who knew no more than she did regarding decision to stop steroid injections. GP did write to Hillingdon Hospital and she was then referred to a Pain Clinic in Uxbridge. Date of appointment is 1/10/18. In meantime has been in ongoing pain. Did leave messages for CCG who got back once but she was out. Advised if she wants to complain to keep trying to get through on phone and to write. Asked if she would keep us updated and if she gets a response to give us a copy. Happy to do that and for us to follow up again.

20/09/2018

X went to see GP and was told she could have some tablets or go private. Not happy with this as feels she takes enough tablets and can't go private. She has since had a letter from Hospital to say has an appointment for procedure on 22/10/18. She is in ongoing pain and not sure appointment will go ahead. Also has an appointment with GP at beginning of October and I advised to ask about other pain management options. Has complained to CCG but it sounds as though they have sympathised only but not offered any other response. Suggested we may like to contact them again depending on how things go. Happy for us to contact her again.

20/09/2018

Mrs X returned my call. She has an appointment to see GP next week. Has child care responsibilities and said would phone us back.

20/09/2018

XX has tried to make appointment with GP but still trying. Has spoken to on phone. However, still in pain and can't always move leg. Strongly advised he make appointment with GP to discuss options and gave number and email for CCG to make a complaint.

24/09/2018

Phoned individual to follow up with them. They went back to their GP but were told there was nothing the GP could do. The individual feels that, having paid into the system all their life, the NHS has let them down badly. They say all they wanted was this one injection, which worked for them. They have had to resort to going private. Gave the individual the contact details for the BHH CCG complaints

department, as the individual wants to lodge a complaint. Also told the individual about asking the GP to make an Individual Funding Request.

27/09/2018

Individual came into the shop to give follow up. Their GP has said they will refer them for physio but cannot offer any other help. They feel the GP didn't have much time for them. AN advised the individual about making an Individual Funding Request, and gave them details of the BHH complaints service.

28/09/2018

Phoned individual to follow up. Their GP recommended that they get acupuncture from Uxbridge Health Centre, Chippendale Way. They have had one session so far and are awaiting a second appointment. We had given them the BHH complaints contacts details, but they have not put in a complaint.

28/09/2018

Called individual for update. Their GP has written a letter to make an Individual Funding Request. GP said it will take up to eight weeks before there is any response.

28/09/2018

Called individual for follow up. They have been referred for a further appointment with the pain consultant (no date given yet).