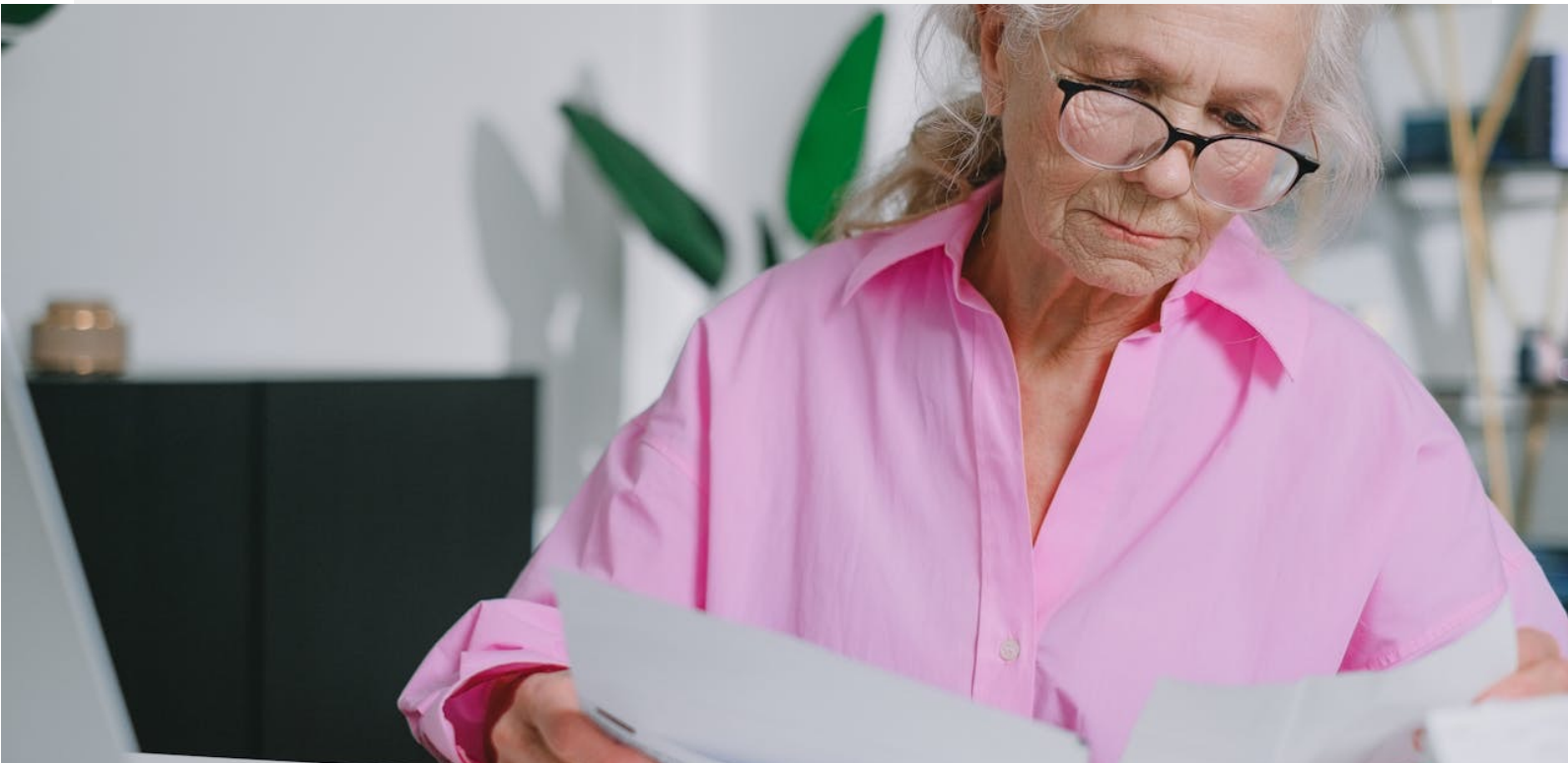


Independent Health Complaints Advocacy Service

Impact & Performance Report

January - March 2024 (Q4)

Supporting residents of West Sussex with their NHS Complaints – providing advocacy in the form of listening to the needs of the client and providing a voice for the individual to be heard.





Feedback from people we have supported

"We are writing to thank your organisation for the help and support provided to us with our complaint."

"We would have struggled through the process that went all of the way to an inquest."

"I truly could not do this without you, and I will always be grateful that you were allocated to me."

"Please pass on our thanks for the very kind and professional way (the advocate) supported us."

"(The advocate) did a really good job of summarising and communicating my needs to pals when I was having a very stressful time. Due to my suffering from several conditions including FND, autism and mental health I was unable to communicate or express myself when dealing with a problem I was having with a local service."

"As always thank you so much for all of your support."

Our service

The demand for IHCAS support is still high, although the workload is manageable and does not currently require use of the waiting list.

The service is still seeing increasing delays with receiving complaint response letters and resolution meetings from the local acute hospital Trusts in West Sussex, as well as also experiencing delays from providers outside of the area.

A high number of the existing cases are complex complaints that require additional time and empathy, especially when supporting clients when their complaint involves the death of a loved one.

Last quarter comparison

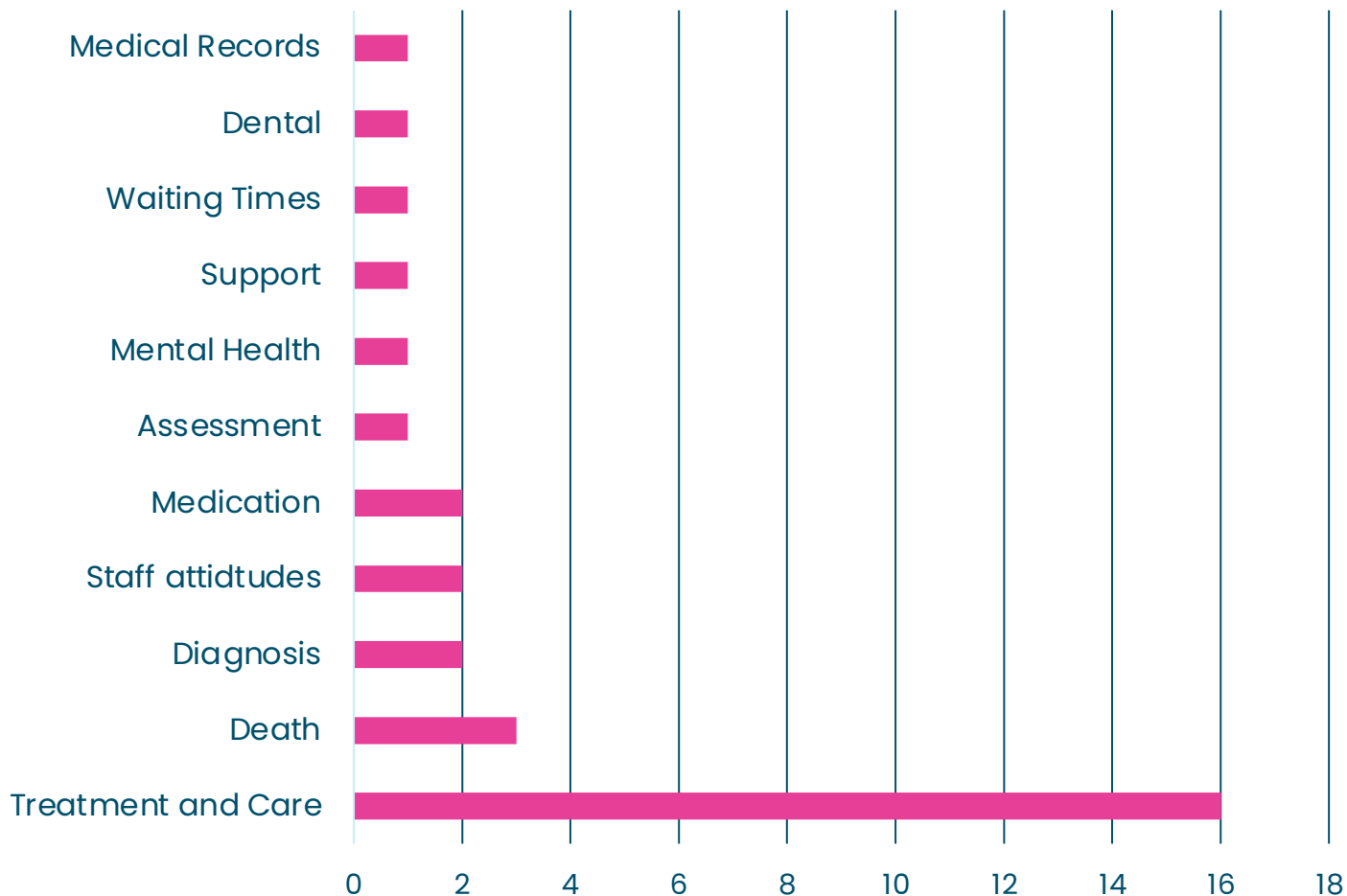
| | Key performance metrics for current and previous quarter | |
|--------------------------------|--|----|
| | Q3 | Q4 |
| One off information and advice | 49 | 30 |
| New cases for support | 31 | 33 |
| People on waiting list | 0 | 0 |
| Advocacy support concluded | 37 | 37 |
| Ongoing advocacy support cases | 57 | 59 |

IHCAS Case Statistics



Themes

New Advocacy Case Themes

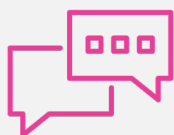


In quarter four, the Team received complaints mostly regarding **'Treatment/Care'** within local Healthcare Providers. There has been a rise of 'Treatment/Care' cases by 20% in comparison to quarter three.

Impact

- One of our Advocates completed their first solo Local Resolution Meeting, with a client that they had been working with since they began working for IHCAS. This resulted in a positive outcome for their client regarding treatment options for their child in an acute hospital Emergency Department.

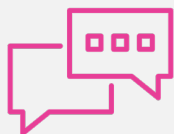
The client provided feedback:



"Glad I was one of your first cases and glad that I was your first solo meeting. We were happy with the outcome, and we couldn't have done it without you"

- One of our advocates assisted a client to challenge a decision not to allow them a personal budget to control who provided their care. Following our assistance, which included a home visit and assisting the client with remote meetings, the client was informed they could now have a personal budget.
- One of our advocates attended a resolution meeting at a Hospital Trust to provide support to a client who was complaining about the death of a relative and poor care the Trust had provided. The meeting resulted in promises for a number of improvements, but the Trust did not arrange a follow-up, so our advocate assisted the client in writing to the Trust to advise how they felt that this was a missed opportunity for learning.
- A client approached the IHCAS service in 2020 following the death of her husband. With support from her advocate, she was able to raise a complaint about the acute hospital Trust and the mental health Trust involved in her late husband's care. The complaint ended up with the parliamentary health service ombudsman (PHSO), which did not uphold the complaint.

The client provided feedback:



"Yes it has been quite a journey, and like you, one that I had hoped would end on a more positive note. However, as with all the big institutions, and the dreaded Covid lurking in the background, it appears that it is increasingly rare to actually get the answers you hope for. I would like to thank you for your dogged determination to get some kind of justice on my husband's behalf in the way he was treated and sadly died during this period. I can honestly say that I believe you have tried all in your powers to help. Myself and my family thank you greatly for your assistance, and words do not seem enough. It was a pleasure to meet you and chat on the telephone on numerous occasions."



Case Study

If you have a cough!

The moral of this case study is, If you have a persistent cough, it is vital that you ensure you are seen by a health professional or you could end up like Gina (name changed) who is now living with stage 4 lung cancer.

Here is her story:

Back in 2016, Gina was under 40 and a smoker. The NICE guidance [NG12] states if you are over 40 and have an unexplained cough, chest pain and shortness of breath, an x-ray should be undertaken within 2 weeks. Gina was 38 and a smoker, she presented herself to her GP 3 times that year and was sent for an x-ray which was thought to be clear, and this is what was reported to the GP.

Moving forward to 2017, Gina had 3 appointments with her GP relating to her cough and shortness of breath. Again in 2018, Gina had 4 appointments with her GP about her cough and shortness of breath, the GP finally at the 5th appointment requested an x-ray. Gina went to her local hospital for the x-ray and within 15 minutes of having the x-ray she received a call from her GP asking her to urgently return to the practice and she was then referred to her local acute hospital on a 2-week rule with suspected lung cancer. After having a biopsy under a general anaesthetic, Gina was diagnosed with small cell lung cancer stage 4.

She started treatment at the end of October 2018, and after having 12 sessions of chemotherapy and also radiotherapy for a small tumour that was found on the top of her spine, she stopped treatment in 2019 but had follow up scans every 3 months. Her husband met the Healthwatch West Sussex engagement team member at a support group and picked up information about the Independent Health Complaints Advocacy Service (IHCAS). Gina contacted the service in May 2020 and was allocated an advocate. Her complaint was submitted to NHS England in July 2020, and whilst this was outside of the normal 12 months' complaint timeframe, it was agreed that due to the circumstances that Gina had been through, her complaint would be accepted and at the end of August 2020, Gina received her response from the GP and NHS England. They had carried out a review of her medical files and had not found any evidence of poor care, and their response stated, **“our reviewer has not identified any particular cause for concern with the care and treatment you have received”**.

Not being satisfied with this response, Gina's advocate arranged a local resolution meeting at the GP practice to enable her to voice her concerns. This meeting took place in October 2020, and after receiving a follow up letter from the GP which she was still not satisfied with, Gina, with support from her advocate submitted her complaint to the Parliamentary and Health Service Ombudsman (PHSO).

Gina also discussed taking legal action against the GP and took advice from a legal service provider. The PHSO took on the case concerning the GP and reported back to Gina in November 2021 that there was no indication that anything went seriously wrong in her case.

However, the solicitor who had taken on the case on a no win no fee basis, looked over all of Gina’s medical files, and was just about to give up when he came across the x-ray taken in 2016. This was sent to a specialist for review and because of that review it was noted that the radiologist had missed “an enlarged lymph node (16mm)”. This was the missing evidence that something had gone wrong in the diagnosis process.

Finally at the end of 2023, Gina settled her case with the radiologist out of court. The money she received has helped the family move forward and build special memories.

Gina was given a 0.1% chance of surviving 5 years, however in October 2023, Gina was told she was cancer free. During this entire period Gina had been supporting her family, she has 3 children, with one child having additional needs. It took a long time for them to accept that their Mum was going to die of lung cancer and so many times Gina had practiced in her head how she was going to say goodbye to her children. When Gina was told that she was cancer free, and explained this to her children, they were understandably very confused and did not understand that firstly they were being told that Mum has 0.1% chance of living and then to be told she is cancer free. Because of this, the children have lost faith and trust in the NHS, they are angry and will no longer visit a GP.

Unfortunately, this process has not ended for Gina. She was told in a call that her scan was clear, but that medical professionals needed to read the full report. Gina reported at the beginning of 2024, that she had a pain in her lung, and she was told the scan was clear, but it was then discovered that there were abnormalities on the scan with her lymph nodes. No one had followed up these abnormalities and she is now currently awaiting the outcome of more tests.

Feedback from Gina:



“On contacting Healthwatch IHCAS, (the advocate) has stood by me throughout the whole process, made me feel listened too, believed and understood. (The advocate) has always remembered to keep in contact and with her support to write this case study has been incredible. I always knew that she believed in me and held my hand and never gave up”

“Gina’s children say thank you for helping Mum”.

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