PCC
PATIENT & CLIENT COUNCIL

PCC Health Committee Briefing Paper - Waiting Lists for Health Care in NI

April 2026

Your Voice,
Our Journey

www.pcc-ni.net

PCC: Waitlists for Health Care in NI

1. We recognise the positive actions taken by the Executive and Department of Health (DoH) to tackle and reduce waiting times and that funding has been matched to the Programme for Government. PCC welcome the recent reflection of the Chair of the Health Committee which acknowledged that "*Our waiting lists here are too long, but some good work has happened. An additional 200,000 people have had elective treatment as a result of the Executive's prioritisation and additional funding. Whilst more needs to be done, that is a good news story*"[1].

2. This briefing document does not reflect or comment on specific waiting time data, but in line with PCC's statutory functions primarily focuses on the public's lived experiences and the impacts of being on waiting lists. It is provided at the request of the Health Committee.

PCC Lived Experience of Waiting for Healthcare Report 2018

15. In 2017/2018 the PCC identified, through our engagement with the public, that waiting lists were increasingly becoming an area of public concern. PCC set out, at that time, to gather information to understand the *"experience and impact on patients waiting longer than the Ministerial target for treatment and care, with a focus on the information available to people to enable them to make informed decisions*[2]*.* In 2018 PCC published the report "**Our lived experience of waiting for healthcare**".

16. Members of the public who participated in this report identified a number of actions that could be taken immediately to address and improve the experience of those currently waiting. These included:

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[1] Northern Ireland Assembly (2026) *Official Report (Hansard) Tuesday 24 February 2026 Volume 189, No 4* Accessed here: plenary-24-02-2026.pdf

[2] PCC (2018) *'Our lived experience of waiting for healthcare.'* Report available on request.

- Having honest conversations about the length of time people will wait so they can make informed decisions about their care;
- Ongoing communication with people to keep them informed of their waiting status;
- Regular updating of waiting lists so that they are an accurate reflection of the situation, and
- Better use of technology to improve communication between patients and professionals and professional to professional.

17. Subsequent to the publication of the PCC's report, the Department of Health established a Departmental-led Task and Finish group in May 2018, with the objective of producing proposals to improve communication with patients referred to an elective care waiting list. Actions were agreed to improve communication alongside a set of principles on communication developed by the Group that should be adopted by the HSC.

18. The set of agreed principles included Transparency, Accessibility, Efficiency, Consistency and Deliverability. The actions agreed were to:

- provide patients with an acknowledgement of their referral;
- advice where information on waiting times will be made available and how often this is updated;
- Consideration to be given to ways in which more general information on the referral system in Northern Ireland could be provided to patients to help them better understand how this works and their role and responsibility in this;
- Information should be provided on waiting times to provide patients with a realistic estimate of how long they will be expected to wait;
- and a patient friendly version of the Integrated Elective Access Protocol should be developed for patients.

NIPSO ‘Forgotten Report’ 2023 and the ‘Follow up’ Communications with Patients Report 2026

19. In June 2023 NIPSO published a report into Healthcare Waiting list communications following emerging themes of poor communications, inconsistent provision of information and how patients were communicated with. Entitled the ‘Forgotten’ Report, it identified significant systemic failings and made 34 recommendations to be taken forward by the Department of Health and the HSC Trusts.

20. The actions and recommendations first identified in 2018 by PCC in our Lived Experience of Waiting for Healthcare Report continued to align with the key recommendations for improvements reflected in the NIPSO Reports.

21. The Public Service Ombudsman has stated in her most recent *“Communications with patients on healthcare waiting lists - Follow-Up report 2026”*[3] that there has been progress in how the Healthcare system provides information to patients on waiting lists.

22. These key improvements include:

- a dedicated ‘Waiting Times’ website allowing people to look up average wait times by Trust, specialty, and clinical urgency. (PCC were engaged by the Department on the best methods to engage the public and representing the public voice in developing the Waiting Times Website).
- A new mobile App ‘My Care’ allowing patients and carers to view personal medical records.
- The introduction of new text and letter notification systems to provide regular status updates to patients and their carers, including ‘long waiter’ texts

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[3] This report is a follow-up to NIPSO’s 2023 ‘Forgotten’ report, an investigation into Healthcare Waiting List Communications

- Revision of and access to IEAP, a more transparent framework explaining exactly how HSC Trusts manage and prioritise their waiting lists, expected processes and patient communication.
- the early development of a ‘support while waiting’ program, designed to help patients manage their physical and mental wellbeing while they are on a waiting list.

23. The Ombudsman has however expressed her frustrations that a “*number of decisions have restricted full implementation of the report recommendations*”.

PCC Waiting Times Data 2025-2026

19. The data and insights set out in this section have been extracted from the PCC Case Management System, which is used by PCC advocates to record the details of the support they provide to members of the public to resolve their issue or complaint. Members of the public can get advice, information or casework support from PCC by calling our freephone line, sending an email, contacting via the website, social media, meeting PCC staff at our in-person walk-in ‘clinics’ at various locations across NI or by coming to a PCC office[4]. The data covers PCC ‘cases’ and ‘contacts’ during the period **1st February 2025 – 28th February 2026**.

20. A **‘contact’** is defined as a call to the PCC freephone service where members of the public’s issue or concern can be addressed by the provision of straightforward advice and information, signposting to another organisation, or the issue can be resolved swiftly, so that they don’t need further dedicated advocacy support.

21. PCC defines a **‘case’** as an issue the public require advocacy support to address, in that it cannot be resolved through the provision of straightforward

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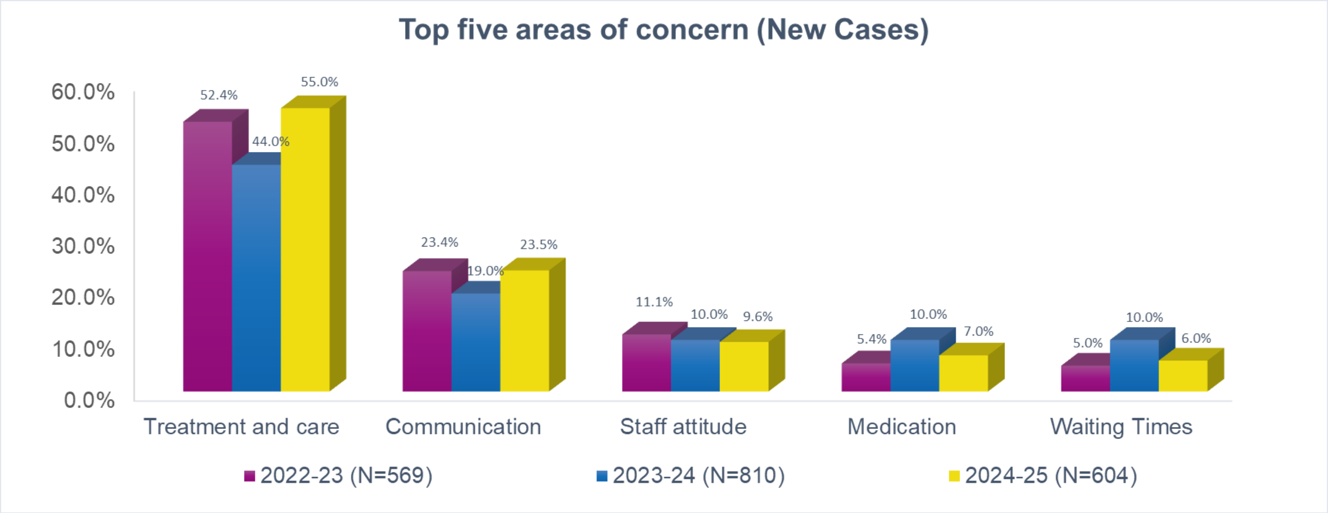
[4] The geographical remit of the PCC is all of Northern Ireland, across the breadth of health and social care including Family Practitioner Services as well as the services provided or commissioned by HSC Trusts. The PCC has local offices in Belfast, Lurgan, Omagh and Ballymena.

advice or information alone. As part of a ‘case’ a member of the public requires advocacy support from a member of the PCC practice team to assist them in achieving a resolution to their issue or concern.

22. PCC are naturally limited in what we can do to directly address waiting lists and waiting times at an individual and systemic level. For instance, when a member of the public comes forward with a concern about waiting times PCC cannot influence their place on a waiting list, however we endeavour to provide relevant support and assistance within the scope of PCC’s role and remit as outlined below.

23. Over the past four years, waiting times have been in the top five areas of concern raised within new PCC cases.



25. According to our most recent data, the issue of waitlists still features significantly and remain a high area of concern for the general public with **103 contacts and 40 cases within the past 12 months** seeking assistance through PCC advocacy support and complaints service. Of the 40 cases this accounts for around 5% of all PCC cases over this period[5].

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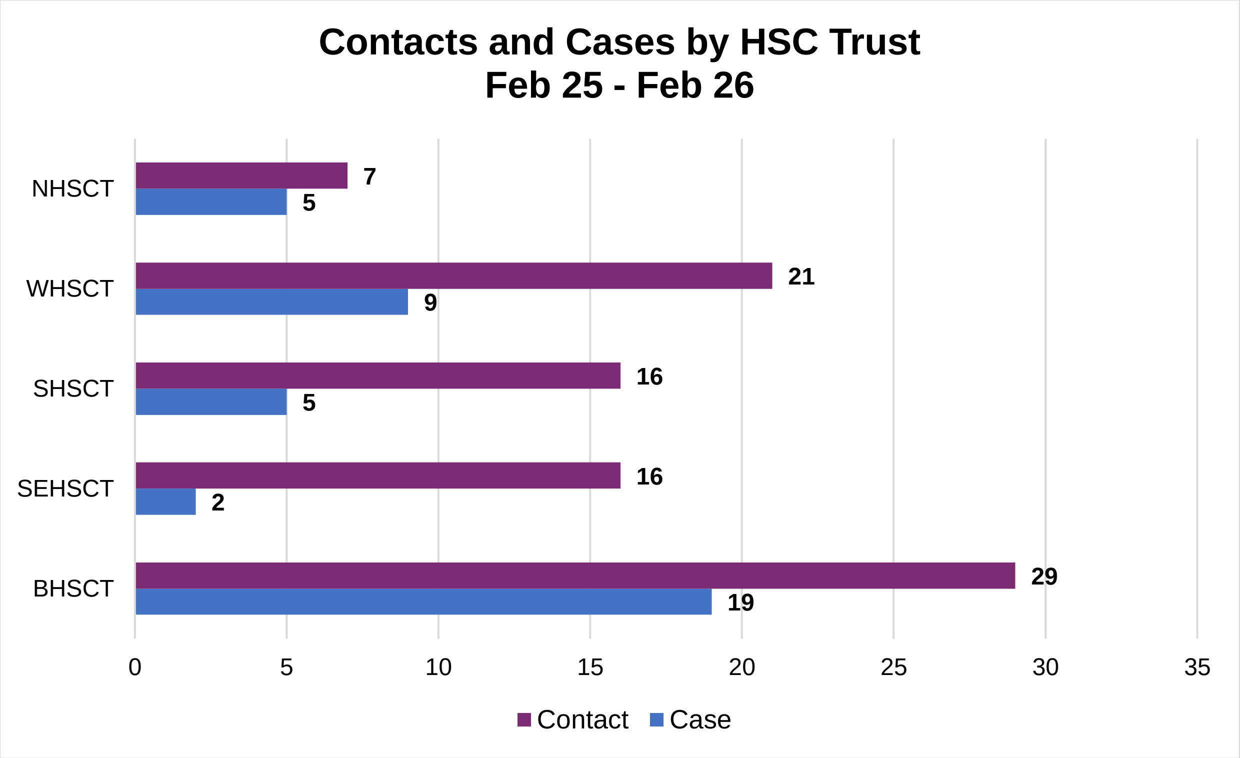
[5] There were 40 cases (not including contacts) referring to this hospital waiting list data, out of a total of 745 cases.



25. There were a wide range of enquiries in relation to waitlists right across the entire healthcare sector with 33 different areas identified. In the 12 months from February 2025 to February 2026, the top five in relation to waitlists were:

    1. Orthopaedics (42)
    2. General Surgery (18)
    3. Ophthalmology (11)
    4. Gynaecology (10)
    5. Rheumatology (7), Neuromedicine/ neurosurgery (7) and Gastroenterology (7)

Themes emerging from PCC data

Themes	Total
Expedite place on waiting list	31
Cross Border/EU Reimbursement	23
Delays	22
Decline	19

Communication	11
Quality of life impact	10
Removed	10
Information (inaccurate or incomplete)	9
Private	7
Referral	4
Support	3
Total	**154**[6]

Summary of themes:

- **Expedite place on waiting list:** these are calls to the PCC from people who were frustrated and concerned about the length of waiting lists and sought support or information from the PCC on making progress up the waiting lists.
- **Cross Border/ EU Reimbursement:** clients calling to seek information on eligibility and how to apply for the cross border/EU waiting list reimbursement scheme. In a small number of calls, clients reported associated issues such as being ineligible due to not having a prior assessment or not being on a waiting list locally, or having previously sought private treatment due to the length of waiting lists.
- **Delays:** these are calls from clients who are experiencing delays in being placed on a waiting list for various reasons including; lack of consultants to diagnose or refer to waiting list; consultants/surgeon willingness to take on procedures due to complications with a condition (in some cases made worse due to length of time on waiting lists); cancellations of appointments; poor communications between Trusts.
- **Decline:** this relates to clients who have reported a deterioration in their condition whilst being on a waiting list, which in some cases has led to associated deterioration in other areas of their lives including in their mental health, professional and family health.
- **Communication:** this is where clients report poor or lack of communication relating to their position on a waiting list, or progress up the waiting list. In such cases, PCC are able to provide a link to the hub to access this information. There were cases of more serious communication issues such as

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[6] The data does not add up to 143 as more than one theme was assigned to certain cases and contacts

clients not being told they were on a waiting list, or those who thought they were on a waiting list only to realise they were being referred for assessment to be placed on a waiting list. PCC Practitioners provide appropriate advocacy support in such instances.

- **Quality of life impact:** similar and with some overlap to a 'decline' whilst on the waiting list, clients report a serious impact to their overall quality of life as a result of waiting for treatment on a waiting list. There were instances of clients clearly stating their mental health has been severely impacted and were signposted for additional support for this. Others mention the impact on their family and their ability to care for children, along with consequences for their professional life too.
- **Removed:** calls here concern clients who were removed from a waiting list without their agreement or prior knowledge. Reasons for this include poor communication through referrals between Trusts/services, clients reported as not having attended appointments but who deny ever receiving them, a change in policy or diagnosis and changes in, or lack of staff involved in the client's care. In several of these cases, clients were reinstated but at the back of the waiting list.

24. The remaining issues in smaller numbers relate to poor provision of information for people on a waiting list regarding progress or significant changes to their place on the waiting list. This includes a few issues with communication between the HSC and Private sector, and people who discovered they were not on a waiting list or had a referral downgraded from 'urgent'. Private healthcare was mentioned several times when people have asked about how to get a referral to private care to expedite treatment, or those who have utilised private care and then had issues around communication or eligibility for further HSC treatment. Some callers also specifically asked if they can have other support or treatment to maintain their health as much as possible whilst awaiting treatment

25. Our data reflects the findings identified in the NIPSO 2026 'Follow Up Report', of inconsistency and variations in frequency and quality of communications provided to patients across Trusts. Consistency in communication with patients

regarding waitlists across all Trusts is necessary. This is evidence that whilst progress has been made, the public are still facing and will likely continue to face, significant challenges regarding waiting lists and their broader impacts.

26. PCC has been making the case for a more **systemic approach to public engagement and participation across the HSC**, along with better triangulation of data and insights within the system. We consider it vitally important that there is a regional approach to collecting, assessing and understanding the lived experience of people on waiting lists and its impacts on them. Impacts can be different for different cohorts of society as outlined below.

Waiting Well – Health Inequalities

27. The impact of remaining on long waiting lists is real, and felt sharply by the public, mentally, physically and emotionally, and is reflected in those raising concerns with the PCC, as outlined above.

28. In 2018 PCC report reflected public comments regarding declining health, and complications in their health. Decreased mental health was often attributed to living in pain or dealing with the uncertainty of waiting on appointments arising from the delays in treatment. Participants described how functions such as sight, hearing, continence and mobility deteriorated while being on a waiting list. In addition, people described the impact on various aspects of their health such as fertility, sleep, weight control and falls, while other participants spoke about a general decline in their condition[7].

29. PCC welcomes the Minister and the Department’s focus on tackling health inequalities and consider it worth examining waiting lists through this lens.

30. The Kings Fund[8] carried out a study in England in 2022, which showed that people who live in the most deprived parts of England were 2.1 times more likely to wait over a year for elective care treatment than people who live in the

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[7] PCC (2018) *‘Our lived experience of waiting for healthcare.’* Report available on request.

[8] Kings Fund (2023) *Tackling health inequalities on NHS waiting lists* Accessed here: Tackling Health Inequalities On NHS Waiting Lists | The King's Fund

most affluent areas. They outlined that this was due to structural, economic and social factors that can lead to differences in the length of time people with the same clinical needs wait for treatment and the differences in the impact waiting has on their daily lives.

31. The issues highlighted included:

- the system being very difficult to navigate
- appointments being difficult to attend for some people
- people reaching waiting lists in different states of health
- people deteriorating at different rates, and
- having caring responsibilities.

32. Our 2025, 'What the Public Think'[9] report showed that many of the public feel they have a lack of agency with regards to their health and social care services:

- 51% Feel disconnected from health and social care services
- 45% of people felt that they were actively involved in their care with healthcare professionals and staff, whilst 30% of people did not.

33. PCC welcomes the Waiting Well plans, funding and engagement within the Elective Care Implementation and Funding Plan. We would welcome an understanding of what information the Department holds in relation to how health inequalities impact upon waiting lists and how the Waiting Well plans will assist those most impacted by waiting in Northern Ireland. Taking a regional and systemic approach to understanding the lived experience and impact of waiting lists is very important in this regard.

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[9] PCC (2025) *What the Public Think.* Accessed here: what-the-public-think-key-findings-from-a-pcc-attitudinal-report-on-people-s-experiences-of-health-and-social-care-and-winter-pressures.pdf

Advocacy Support

34. There are clear benefits of advocacy support in assisting and supporting people regarding their health and social care issues, including waiting lists. This is evidenced by the following PCC case study:

Case Study from PCC Advocacy Casebook 2025

BACKGROUND

David, who is in his early forties, has been living in pain with a medical condition. David's pain was so unbearable that he attended his GP over twenty-six times in a six-month period as well as attending his local Emergency Department, sometimes by ambulance. He was told he was on the waiting list for a procedure but didn't have any further information as to when this would happen. David was frustrated with the lack of treatment and felt he was being bounced between services. David was concerned that he now had a fractured relationship with the healthcare professionals because of the many attendances and reported a breakdown in communication with the consultant. It was at this point David made a complaint to the Trust. David received a response to his complaint but felt it did not address his concerns. As time went on, David began to feel depressed, he spent most of his day in bed which impacted his family life and he lost touch with his social circle, leading to a decline in his mental health. After seeing an advert for the Patient and Client Council (PCC), David made contact for advice.

WHAT WE DID

Our Advocate listened to David and agreed an advocacy plan. With David's consent, our Advocate re-established contact with the services to find out what treatment pathway he needed to be on to manage his condition until the surgical procedure took place. Our Advocate contacted David's consultant to emphasise the deterioration in David's condition since David was last seen.

OUTCOME

David was seen by his consultant and together they are working on a treatment plan, which includes David having regular direct contact with the service and a programme of re-education and changes to his medication, working alongside his GP and Primary Care Team. David said the change to his life has been great and that he and his family are grateful for the support received from the PCC.

This Case Study is featured in our Advocacy Casebook, which is available on the PCC's website: PCC Advocacy Casebook

35. Advocacy:

- Safeguards people who can be treated unfairly as a result of institutional and systemic barriers as well as prejudice and individual, social and environmental circumstances that make them vulnerable.
- Addresses power imbalances for people who need a stronger voice by enabling them to express their own needs and make their own decisions.
- Enables people to gain access to information, explore and understand their options, and to make their views and wishes known.
- Speak up on behalf of people who are unable to do so for themselves.

36. The availability of independent advocacy assists in creating a culture of openness and transparency and plays a fundamental role in governance, assurance and addressing health inequalities.

37. PCC believe that appropriately supporting independent advocacy services provides a level of assurance that HSC Trusts and organisations are committed to being learning organisations, committed to meeting their Statutory Duty of Quality, are appropriately invested in the Duty of Candour and, most importantly, to protecting patients[10].

38. Advocacy services are not currently commissioned on a regional basis, to an agreed, or, required standard, with related training, support and governance mechanisms. The PCC expects, and we believe the public expect, that organisations providing advocacy services should be **independent of service providers i.e. structurally, financially and psychologically independent**. The availability and accessibility of independent advocacy assists in creating a culture of openness and transparency, and plays a fundamental role in governance, assurance and addressing inequality.

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[10] PCC (2025) *PCC response to the Being Open Framework consultation.* Accessed here: being-open-framework-pcc-response.pdf

Waiting List Reimbursement Scheme

39. It is recognised that initiatives such as the Cross-Border/EU Surgery reimbursement scheme are being introduced due to the extreme pressures. It is important that they are entered into with a considered understanding of what this might mean for the public and for the HSC system in the medium to longer term, and that information is made available to assist people to make an informed decision. PCC notes potential implications for follow-up or wrap-around care arising outside of these initiatives, or for accessing care provision when things go wrong. Due to jurisdictional considerations and the parameters of PCC’s role and remit, the PCC cannot provide advocacy support for surgery and procedures delivered outside of UK and in the independent sector.

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