



“the lack of communication has led me to feel **forgotten**, worthless.”

“feel like no one wants to help me that I have been **forgotten** about and not important.”

“Actually, communication of any sort would be appreciated, you feel you make it on to a waiting list and are completely **forgotten** about.”

“Feel... are **forgotten** and a burden asking about you were entitled to.”

“Forgotten left in... was...”

'Forgotten'

An investigation into **HEALTHCARE WAITING LIST COMMUNICATIONS** by the Northern Ireland Public Services Ombudsman



Ombudsman's Foreword

In April 2022, I commenced an Own Initiative¹ investigation into the communications provided to patients and/or their carers following placement on a waiting list.

The management of Northern Ireland Healthcare Waiting Lists is a complex issue, which has undergone significant public scrutiny and review. Whilst recognising the planned work to improve waiting lists², and the considerable pressure which health staff continue to face within a challenging financial environment, I remained concerned that patient communication has been relatively overlooked.

It is understandable, in light of the current health crisis, that priority is given to adapting and investing in Health Services to reduce waiting times. However, the pursuit for improvement should not divert attention from the importance of keeping patients updated.

The primary focus of the investigation is the adequacy of Trust communications to patients, and/or their carers, across various stages of the waiting list process, with significant consideration being given to the content of the Integrated Elected Access Protocol (Department of Health guidance), and its application by the Trusts.

The objective was to determine whether or not systemic maladministration³ has arisen within the communication practices of the Northern Ireland Health and Social Care Trusts (the Trusts) and whether improvements are required. My office also aimed to publicise what patients and/or their carers should expect from waiting list communications.

The Investigative Methodology drew evidence from a wide range of sources. This included extensive queries and information requests to the Trusts and the Department; a General Public survey (with 646 responses); a General Practitioner (GP) survey (with 321 responses); follow up interviews with a number of General Public and GP survey respondents; and a number of Case Study reviews.

1 Section 8 of the Public Services Ombudsman Act (Northern Ireland) 2016

2 [doh-elective-care-progress-report-oct-2022.pdf \(health-ni.gov.uk\)](https://www.health-ni.gov.uk/doh-elective-care-progress-report-oct-2022.pdf)

3 Systemic maladministration does not have to be an establishment that the same failing has occurred in the 'majority of cases', instead it is an identification that the same issue/failing has repeatedly occurred and is likely to occur again if left unremedied; or alternatively, an identification that a combination or series of failings have occurred throughout a process which are likely to occur again if left unremedied

Overall, my investigation found that although communication with patients appears to have been considered a priority in the past, longstanding non-compliance with written guidance, and a failure to monitor and address these issues, suggest that the focus of waiting list processes has moved away from being patient centred. Instead, patients are too often provided with little to no communication on the progress of a fundamental aspect of their lives, leaving them to feel forgotten.

I consider that the significant and repeat failures identified during my investigation amount to systemic maladministration. I welcome the Trusts' early acknowledgement that improvements are required, and their assurance that steps are already being taken to implement my recommendations. I also note the concerns raised by the Department in relation to the financial implications some of my recommendations may have:

‘The context within which health and social care services are currently provided is extremely challenging...That situation has been compounded by the 2023-24 Budget announced by the NI Secretary of State on 27 April which has a funding gap of some £732million for Health and Social Services this financial year. Like all other Departments in Northern Ireland, the Department of Health is in an impossible position of being asked to fulfil conflicting responsibilities. This involves trying to balance our responsibilities to live within the budget we have been given, act in the public interest and safeguard services...’

I recognise the significant challenges faced by the Trusts and the Department, and I give a commitment that I will fully consider any financial and/or logistical reasoning put forward as to why any of my recommendations cannot be implemented as intended. I will also consider any proposed alternative action suggested as a replacement in these cases.

However, I am cognisant that with rising waiting lists and longer waits, good communication has become key to patient's *'waiting well'*. I am also in no doubt that the current lack of communication has not only had an impact on patients, it has also impacted on the resources of the Trusts and GPs due to the resulting level of enquiries and complaints. I therefore consider that better communication from the outset will reduce the impact on both patients and Trust resources.

I look forward to engaging with both the Department of Health and the Trusts to ensure appropriate and reasonable steps are taken to address the failings identified within my report.



Margaret Kelly

Northern Ireland Public Services Ombudsman

June 2023

Executive Summary

The Principles of Good Administration

When undertaking an investigation, my office tests the actions of public bodies against the Principles of Good Administration⁴ (the principles).

Each chapter of my report focuses on a particular stage of the waiting list process and analyses the communication processes within each stage against all relevant principles. This Executive Summary condenses the findings and recommendations.

Getting it right – Applying guidance

'All public bodies should act according to their statutory powers and duties and any other rules governing the service they provide. They should follow their own policy and procedural guidance, whether published or internal... When they decide to depart from their own guidance, recognised quality standards or established good practice, they should record why...'

Extract taken from First Principle of Good Administration

Central to public bodies 'getting it right' is the consistent application of guidance. In the case of waiting lists, Trusts are expected to apply the Department's Integrated Elective Access Protocol (IEAP)⁵, which includes several directions on expected patient communication.

Overall, my investigation identified inconsistent implementation of the IEAP, with evidence of longstanding, widespread non-compliance in the following areas:

- **Annual review:** The Department failed to annually review the IEAP between 2009-2020. This requirement was subsequently amended in the 2020 IEAP (published in 2021) replacing an 'annual' review to 'regular' review;
- **Acknowledgements:** Trusts are required to send an Acknowledgement to patients following receipt of their referral. All Trusts have failed to consistently comply with this direction. Two of the five Trusts state that they had no intent to reinstate the practice, while those who have reinstated acknowledgements are inconsistent in their approach;
- **Outcome of Triage:** Once a referral is received by a Trust it is assessed (triaged) by a health professional and assigned a clinical urgency, i.e. Red Flag/Urgent/Routine. The majority of specialties within the Trusts do not communicate these Triage outcomes to patients;
- **Staff sign off:** Relevant Trust staff are required to not only read the IEAP but to sign off that they have read it. All Trusts confirmed that their staff do not sign off the Protocol.

The investigation also identified a lack of clarity around who is responsible for monitoring compliance with the IEAP. Although the Department confirmed that in some cases it was aware of areas of non-compliance, it took no action to reinforce the IEAP. Instead, the Department suggested that compliance with patient communication directions cannot be monitored.

4 [0188-Principles-of-Good-Administration-bookletweb.pdf \(ombudsman.org.uk\)](#)

5 [INTEGRATED ELECTIVE ACCESS PROTOCOL \(health-ni.gov.uk\)](#)

Being customer focused – Accessible information

'Public bodies should provide services that are easily accessible to their customers. Policies and procedures should be clear and there must be accurate, complete and understandable information about the service...'

Extract from Second Principle of Good Administration

As waiting list information and advice, are not provided to all patients within standard correspondence, the onus is often placed on the patient and/or their carer to seek out this information. My investigation identified significant concerns with the accessibility of this information:

Unmet and incomplete IEAP directions

95%

of General Public survey respondents indicated that they have not been kept informed

The IEAP refers to its purpose being to inform patients of the approved processes for managing waiting lists.

However, patients are unable to depend on the Protocol to advise them of what to expect as several of its patient communication directions are not followed, and many fall short of addressing the level of patient communication required.

No contact information

69%

of General Public survey respondents indicated that they would like to request information, but they do not know who to contact

As patients may not receive any correspondence from the Trust until the point they are booking an appointment, they are unlikely to hold direct contact details to seek out information or advise of changes in circumstances. Although contact information is available online, it is often generic.

In addition to inaccessibility of information this can also contribute to patients failing to advise of changes in circumstances. A lack of direct access to appropriate contact information, and a lack of communication which could remind patients of the importance of updating the Trusts, may result in incorrect/outdated patient information being held by the Trust. This may in turn result in letters being sent to the wrong address.

Lack of information online

42%

of General Public survey respondents indicated they felt unable to request information

Those who feel unable to request information directly from the Trust are faced with limited options to access information.

Trust websites typically hold limited waiting list information,⁶ with only two of the five websites publishing general wait times reports. In both cases the report is held in a section entitled ‘Corporate Information’, an area which the general public may not choose to access.

None of the websites hold a copy of the IEAP, while only one makes reference to the guidance⁷. However, it is noted that in the weeks ahead of publication of my report the Department launched its ‘My Waiting times NI website’⁸ which provides average wait times for general specialities.

Limited information available to General Practitioners

80%

of GP survey respondents indicated that waiting list information is not easily accessible to them

The majority of GPs are not directly provided with general wait times by the Trusts, and many are unfamiliar with the IEAP⁹. They are therefore unable to, and are not required to, provide waiting list advice to patients beyond the point of referral.

The Trusts’ apparent reliance on GPs to provide waiting list information to patients is therefore misplaced and leads to potential confusion as to whom patients should be contacting for updates.

Lack of provision of Clinic Letters

88%

of General Public survey respondents feel like they have been forgotten

Despite best practice publications, and GB counterparts, recognising the importance of sharing written clinic summary information with patients, only one of the five Trusts has recently introduced this process. All other Trusts typically provide this correspondence solely to the patient’s GP.

Being open and accountable – Providing relevant, informative, waiting list information

‘Public administration should be transparent and information should be handled as openly as the law allows. Public bodies should give people information and, if appropriate, advice that is clear, accurate, complete, relevant, and timely. Public bodies should be open and truthful when accounting for their decisions and actions...’

Extract from Third Principle of Good Administration

6 During finalisation of my report the Department launched the My Waiting times NI website [My Waiting Times NI - DOH/HSCNI Strategic Planning and Performance Group \(SPPG\)](#) – formerly HSCB

7 [Appointments | Northern Health and Social Care Trust \(hscni.net\)](#)

8 [My Waiting Times NI - DOH/HSCNI Strategic Planning and Performance Group \(SPPG\)](#) – formerly HSCB

9 95% of GP respondents to our survey indicated that they were not familiar with the Protocol

My investigation identified a lack of openness and transparency in waiting list communications, often resulting in patients/carers being negatively impacted:

NIPSO General Public Survey response statistics



Initial Stage: Referral

The potential impact of limited information can first be identified at the outset of the waiting list process when a patient is referred to a specialty. At this point, the health professional sending a referral, will assign a 'Clinical Urgency' (Red Flag/Urgent/Routine) and will often verbally communicate this to the patient.

However, many patients, including 54% of our General Public survey respondents, are unaware that when a referral is subsequently received by a Trust, it is reassessed (triaged). This means that the Clinical Urgency assigned by the health professional who sent the referral may change. Where changes occur, the Trust does not inform the patient, despite this often having a significant impact on both expected waiting times, and potentially the patients' health and well-being:

Case Summary taken from Chapter 4, Case Study 5:

In this case a patient, who has profound learning difficulties, complex needs and co-morbidities, had their Urgent GP referral downgraded to Routine by the Trust. The patient's family member only became aware of this 6 months later when they contacted the Trust to find out when the patient would be seen.

Patient family member reflection:

'The downgrading resulted in the waiting time to receive a first out-patient appointment being turned from months to years...'

Acknowledgement

Once a referral is triaged, patients either receive no communication from the Trust until they reach the point of agreeing an appointment, or the acknowledgement they do receive provides limited information. A patient may therefore never receive, or potentially wait years to receive, information to confirm:

- their referral has been received;
- their allocated Clinical Urgency (Red Flag/Urgent/Routine);
- general wait times;
- who to contact for queries or changes in circumstances; or
- what to expect.

This lack of information can lead not only to distress, frustration, and anxiety, but also to administrative errors going unnoticed, particularly as many patients are reluctant to make contact with the Trusts¹⁰:

Case Summary taken from Chapter 3, Case Study 4:

In this case a patient was seen and assessed as requiring surgery by a private clinic through a waiting list initiative. The patient was subsequently transferred back to the care of the Trust, under the belief they had been added to a waiting list.

Years later, after no communication, the patient, and their GP queried the delay.

A consultant assessment was eventually arranged where the patient was recorded as being 'lost to follow up'.

6 years after the patient was first identified as requiring surgery, they were placed on a surgical waiting list.

Patient reflection:

'Well, the impact of no communication whatsoever, for five years, I was literally just left in limbo, you know, it does affect your mind... So a letter, might not be no big deal to the people sending the letter out to you, maybe they haven't sent it to you or they should have sent it to you or you're lost in the system. That's still one human being who's left in limbo... the person that this is happening to hasn't got a clue what's happening at the other side...'

Updates/Removal

After a patient is added to a waiting list, the communication typically remains poor. Updates are not provided as standard to advise of waiting list progress, or to encourage patients to advise of changes in their circumstances or medical condition.

My investigation found instances where patients were not informed of fundamental issues within the service, even though those issues were significantly impacting upon the waiting list. Responses to our surveys also suggested that patients are not typically offered an appropriate explanation as to why they are removed from a waiting list following a Clinical Validation review.

Instead, patients are often left in the dark, finding themselves unable to plan ahead, and becoming frustrated if they pursue information for themselves only to find that they have not progressed as anticipated.

Complaint responses

Many of the cases reviewed during the investigation identified individuals having to repeatedly raise queries and complaints over prolonged periods of time before relevant information was provided. In some instances, information was knowingly withheld:

¹⁰ 44% of General public survey respondents indicated they do not want to put additional pressure on the Health Service by querying their position

Case Summary taken from Chapter 5, Case Study 11:

In this case the patient's family had complained to both the Trust and the Service in relation to waiting list progression. On multiple occasions they requested information to explain the reason for the delays and what the Trust were doing to rectify any issues.

Within an internal email discussion, Trust Staff specifically highlighted that the reasons being discussed should not be shared within the response to the patient's family:

'For background and not for complaint response: The Trust attempted to source outside support from the Tavistock clinic, England in 2018 with no success. A waiting list initiative is not appropriate for this service given that a typical patient journey from assessment to transition completion is around 7-8 years (in a straightforward case). Given there are 350 patients on the waiting list, with no individual having a clinical priority over anyone else, any deviation from the current service could need to be a direction of HSCB. The Trust has been raising the difficulties within this service with HSCB and DOH for several years. We are currently awaiting a HSCB review of the service to commence in the Autumn 2019.'

Rather than provide this information in the subsequent response, the family were instead advised of the increase in demand for the service.

Acting fairly and proportionately – Treating individuals in similar circumstances, in a similar way

'...People should be treated fairly and consistently, so that those in similar circumstances are dealt with in a similar way. Any difference in treatment should be justified by the individual circumstances of the case...When taking decisions, and particularly when imposing penalties, public bodies should behave reasonably and ensure that the measures taken are proportionate to the objectives pursued, appropriate in the circumstances and fair to the individuals concerned....'

Extract from Fourth Principle of Good Administration

My investigation identified repeat instances where variation and inconsistencies in waiting list communications resulted in a significant level of unfairness to patients, including the following areas:

- **Acknowledgements:** The variation in provision and content of acknowledgements across the Trusts means that some patients/carers are better informed than others on their waiting list status, based solely on which Trust, and specialty, they are referred to.
- **Partial booking letter:** The variation in approach to this correspondence, across the Trusts, means that Patients/carers are being provided with varying timeframes to make contact to book an appointment. This includes some being provided with longer notice of potential removal penalties than others.
- **Removal/Discharge Letter:** A Trust wide policy is in place to allow a patient to request reinstatement to a waiting list within four weeks of removal, for example following nonattendance to an appointment. However, only certain Trusts and specialties publish this information within patient communications. Therefore, despite all patients being able to request reinstatement, some will not be informed of their ability to do so.

Putting things right & seeking continuous improvement

'When mistakes happen, public bodies should acknowledge them, apologise, explain what went wrong and put things right quickly and effectively...'

Extract from Fifth Principle of Good Administration

'Public bodies should review their policies and procedures regularly to ensure they are effective...and capture and review lessons learned from complaints so that they contribute to developing services'

Extract from Sixth Principle of Good Administration

In 2018, the Patient and Client Council (PCC) published a report¹¹ highlighting concerns in relation to waiting list communications. In its conclusion, the report suggested that Trusts implement ongoing communication with patients to keep them informed.

Five years on, my investigation has identified that little has been '*put right*'. Not only are patients not being provided with an appropriate level of waiting list information, they are also faced with the requirement to persist with queries and complaints in order to access information.

This lack of reflection was also identified in the Department's failure to review the IEAP. A significant period expired whereby no review or updates were undertaken, despite significant non-compliance with the guidance.

However, I acknowledge that the Department are taking steps to improve the level of information available to patients, including the recent introduction of the '*My Waiting times NI*' website and the anticipated introduction of a digital integrated care record (Encompass). Whilst these two initiatives will not address all the improvements needed in relation to waiting list communications, they do have the potential to significantly improve the level of information currently available to patients.

Recommendation Summary

Getting it right:

The IEAP should be revised to incorporate all changes required by the report recommendations. Revision should include (but not be limited to) clear instruction on expected patient communication; accepted reasons for departures from guidance; and monitoring compliance.

Training on the revised IEAP should be provided to relevant Trust staff.

Based on Recommendations 1.1,1.2,3.3,3.4,4.1,5.2,6.1

Being customer focused:

Consideration should be given to improving patient accessibility to waiting list information. This should include the introduction of a dedicated waiting list information section within each of the Trust websites where general information on waiting lists can be centralised.

Engagement sessions with General Practitioners should be arranged to discuss patient communication and awareness of the IEAP.

¹¹ 'Our lived experiences of waiting for healthcare, People in Northern Ireland share their story' PCC March 2018

Patients should be provided with a copy of clinic letters. Guidance on the provision of clinic letters, including exceptional circumstances where letters should not be sent to the patient, should be published.

Based on Recommendations 1.3,2.2, 2.4, 4.2, 6.6, 7.1, 7.2, 7.3, 8.1, 8.2

Being Open and Accountable:

An acknowledgement template should be introduced and used by all Trusts and specialties. This template should include Clinical Urgency; general wait times; what to expect and who to contact for further information/change in circumstance. Updates should be provided to those waiting 6 months or longer and include encouragement to advise of changes. Compliance with the provision of acknowledgements should be monitored.

Waiting list patients should be advised of fundamental changes or issues with services. They should also be provided with an appropriate level of reasoning for removal from waiting lists following clinical validation.

Refresher training should be provided to all staff involved in the provision of waiting list information to patients/representatives to ensure that openness and transparency is at the forefront of all responses.

Based on Recommendations 3.1,3.2, 3.5,3.6,4.1, 5.1, 6.4, 8.3

Acting fairly and proportionately:

A standard partial booking template should be used across all Trusts, providing consistent advice on response timeframes and potential removal advice.

All discharge letters (where relevant) should provide advice on the four week reinstatement policy.

Based on Recommendations 6.2, 6.3, 6.4

Putting things right & Seeking continuous improvement:

Additional steps should be taken to promote the work of the WLMU, and Encompass, to the general public. This should include the publication of information within Trust websites.

The current limitations of Encompass, in relation to waiting list information, should be considered and addressed.

Based on Recommendations 9.2, 9.3



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