'Forgotten'

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

OWN INITIATIVE
REPORT

Glossary

ADHD	Attention Deficit Hyperactivity Disorder
AHP	Allied Health Professional
BOIS	Belfast Orthopaedic Information System
CCG	Clinical Communication Gateway
CNA	Could Not Attend
DNA	Did Not Attend
GIC	Gender Identity Clinic
GP	General Practitioner
HSCB	Health and Social Care Board
IEAP	Integrated Elective Access Protocol
IPA	Independent Professional Advice
NICCY	Northern Ireland Commissioner for Children and Young People
NIECR	Northern Ireland Electronic Care Record
NIPSO	Northern Ireland Public Services Ombudsman
NISRA	Northern Ireland Statistics and Research Agency
PAS	Patient Administration System
PCC	Patient and Client Council
PRSB	The Professional Record Standards Body
RCGPNI	Royal College of General Practitioners Northern Ireland
SPPG	Strategic Planning and Performance Group
WLMU	Waiting List Management Unit

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Ombudsman's Foreword

In April 2022, I commenced an Own Initiative[1] 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 lists[2], 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 maladministration[3] 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)
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

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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.

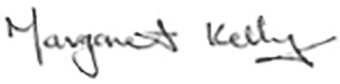
I consider that the significant and repeat failures identified during my investigation amount to systemic maladministration. I welcome the Trusts' early acknowledgement that improvements are required, and their assurance that steps are already being taken to implement my recommendations. I also note 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

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Executive Summary

The Principles of Good Administration

When undertaking an investigation, my office tests the actions of public bodies against the Principles of Good Administration[4] (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)

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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 guidance[7]. 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 IEAP[9]. 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

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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

33% *indicated that their circumstances changed while waiting and they were unaware of whom to contact*

47% *indicated they may have considered private treatment had they been informed about the extent of the waiting time*

24% *indicated that a lack of information led to mismanagement of their care and treatment*

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.

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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 Trusts[10]:

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

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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.

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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 report[11] 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

Background

Why investigate Waiting List Communications?

"A lack of information means I am unable to decide on a solution, perhaps outside of the NHS, and makes me feel forgotten about thereby increasing anxiety."

Patient

"I have been on the waiting list since April 2018. Since then I have received one letter ...This has caused me stress and anxiety. I feel forgotten about and worried that I've somehow maybe fallen off the list."

Patient

"My mental health has deteriorated, I still don't know where exactly I am on the list as the Trust refuse to tell me despite my asking and questioning within my complaints."

Patient

"It has left me anxious not knowing for 3 years now if I was even on a waiting list. I had to find out myself, GP could not tell me."

Patient

"Lack of information had left me in limbo."

Patient

"Condition worsens, no support or basic info so extra stress and worry. The holistic nature of impact not addressed or recognised."

Patient

"Feels as though you are forgotten about and a burden for asking about a service you were offered and entitled to."

Patient

"I received zero communication from the Trust. Zero. Not a confirmation of being transferred from my GP, not a confirmation of being on a waiting list, nothing. This added an untold amount of stress, anxiety, and worry. It severely impacted my mental health and is simply unacceptable."

Patient

"I didn't have enough information about where I was on the list and how long I could potentially wait for surgery. I feel I didn't have sufficient information to empower me to make informed choices e.g. whether or not I should opt to have the surgery privately."

Patient

"I have no idea if...or when I was or will be placed on a waiting list.... and I feel as though they don't care....I do understand that they are under pressure....but a quick email.... letter...or call would help....."

Patient

"Lack of communication - uncertain if successfully on the list, where I am on it, how long wait will be. Leads to me needing to make phonecalls to find out, which is often beyond my limits without causing my health to flare up."

Patient

"Lack of information/ confirmation creates mistrust and uncertainty which is detrimental to the belief that there is equality in the availability of healthcare."

Patient

"There was no indication of the waiting list being so long and if I had been given this information I would have considered other options as this situation is now effecting my ability to work."

Patient

"Feel like I've been forgotten about. I'm unsure if I'm still on lists. I can't get health insurance until I have been seen by consultant."

Patient

"My mental health has suffered as I am unaware if the surgery will ever be performed."

Patient

"Feel forgotten, a nuisance. Cannot make plans. Life is on hold especially as I am unable to do so much pending this treatment. Mental health is now an added problem due to delay and lack of communication."

Patient

"Not knowing where I stand, what I can do. Also knowing that if I had gone private at the start I would not have lost 2-3 years of living with potential manageable condition."

Patient

"I had a four year wait for urgent major surgery. The excessive wait impacted on all my aspects of my life in a negative way. I had no communication from the Trust throughout this wait and unless I requested information nothing was provided... I was upset, angry, frustrated and felt hopeless with nowhere to turn to for help.... I suffered from depression as a result of the excessive wait and the helplessness in accessing information and updates. The feeling of having to be the person to contact the Trust to seek information made me feel like I was harassing them and that this could negatively impact my care, but I was at a loss of what to do."

Patient

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Background and Decision to Investigate Waiting List Communications

The management of Northern Ireland Healthcare Waiting Lists is a complex issue, which has undergone significant public scrutiny and review. Statistics published by the Northern Ireland Statistics and Research Agency (NISRA), and the Department of Health (the Department), show that as of 31 March 2023, just over 49% (197,345) of patients waiting for a first outpatient appointment[12], and nearly 53% of patients waiting for an inpatient or day case admission, had been waiting for over 52 weeks.[13]

A research paper prepared for the Northern Ireland Assembly in December 2021, further identified that *"NI waiting times have been reported to be the worst in the United Kingdom, and amongst some of the worst in Europe"*, with the then Health Minister, indicating that it could take *'up to 10 years'* to resolve the issues[14].

Whilst recognising the ongoing and planned work[15] to improve waiting lists, and the considerable pressure which health staff continue to face, I remained concerned that patient communication continued to be relatively overlooked.

I was particularly concerned as, despite this being an area already highlighted as in need of improvement within a 2018 Patient and Client Council[16] report, the Office continued to see themes of poor communication raised within complaints, with individuals voicing considerable frustration, distress, and anxiety as a result:

'My GP referred me on that day. Since then I have heard nothing. Not a phone call. Not a letter. Nothing. I am still waiting for any information on how my medical treatment will proceed 2 years and 7 months later.'

Patient

'The silence and lack of information was devastating on top of circumstances in which I learned I had cancer... I feel angry that I was left without any source of specialist support and information for nearly one month following the poorly revealed diagnosis.'

Patient

Extracts taken from NIPSO complaints

Early observations also raised concern that Trusts potentially had an inconsistent approach to communication, with some patients being provided with more information than others, dependent on the Trust or medical specialty they attended.

12 Northern Ireland Outpatient Waiting Time Statistics (nisra.gov.uk)
13 Northern Ireland Inpatient and Day Case Waiting Time Statistics (nisra.gov.uk)
14 Dr Lesley Ann Black, Eileen Regan and Marta Cipriano, *"The unhealthy state of hospital waiting lists: what we know, don't know, and need to know"*, Paper 79/21 NIAR 171-21, 10 December 2021
15 doh-elective-care-progress-report-oct-2022.pdf (health-ni.gov.uk)
16 *'Our lived experiences of waiting for healthcare, People in Northern Ireland share their story' PCC March 2018*

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For that reason, in February 2022, I wrote to the Department, and the Health and Social Care Trusts (the Trusts), explaining that I was considering an investigation into the communications provided to patients and/or their carers when placed on a waiting list. In response, all Trusts accepted that there is no consistent approach applied to waiting list communications, and that improvements are required.

Following external engagement, feedback was also received from a range of bodies, supporting that communications require improvement:

'I am pleased to hear that you intend to take action relating to hospital waiting lists and the information provided to patients'

Commissioner for Older People for Northern Ireland

'...we consider that the communications provided by Health and Social Care Trusts to patients on waiting lists to be inadequate. The current approach differs significantly across all five Health and Social Care Trusts and is not consistent[17]*'*

Royal College of General Practitioners Northern Ireland

'...This fourth element was headlined Elective accountability And Transparency and we state: ...We need to have an honest conversation with patients. They deserve to know when to expect their surgery, how long they will wait and what they can do to "wait well".'[18]

Royal College of Surgeons England (NI)

'I welcome your intention to conduct such an investigation into the administration of communication to patients and their carers on healthcare waiting lists... the need for improvements in information and communication between families and services was a key issue... many parents/carers referred to spending a lot of time "chasing appointments" or ringing around different people to get updates or information'

Northern Ireland Commissioner for Children and Young People

At that time, the Northern Ireland Commissioner for Children and Young People (NICCY) had recently completed a rights based review of Child Health Waiting Lists in Northern Ireland, *'More Than a Number'*,[19] and advised that a lack of communication was regularly identified as an issue by patients and/or their carers.

The Northern Ireland Audit Office (NIAO) also indicated its own concerns in relation to waiting list management and its intention to review '*Elective Care Waiting Lists*'. This review, which NIAO aim to publish in Summer 2023, assesses waiting time trends and performance against targets, as well as reviewing why waiting times have deteriorated, and the effectiveness of previous and current initiatives to reduce waiting times.[20]

Having considered the available evidence, as well as responses from the Department, Trusts and other third parties, the investigation was publicly announced on 19 May 2022.

17 Extract from Royal College of General Practitioners Northern Ireland response to NIPSO February 2022
18 Royal College of Surgeons England (NI) Manifesto Stormont 2022 Elections
19 more-than-a-number-child-health-waiting-lists-in-ni-final-19-october-2021.pdf (niccy.org)
20 Work in Progress - Elective Care Waiting Lists | Northern Ireland Audit Office (niauditoffice.gov.uk)

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I considered that an investigation, which facilitated the comprehensive examination of waiting list communications, had potential to identify best practice, and deliver findings and recommendations that would have a meaningful impact on patient experience in Northern Ireland.

The Scope: Communications provided to Patients and/or their Carers when on a Waiting List

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.

The Department and Trusts advise that the effective management of outpatient, diagnostic and inpatient waiting lists is set out within a step-by-step Department Protocol. This document is called the Integrated Elective Access Protocol (IEAP). The investigation therefore gives significant consideration to the content of the IEAP, and its application by the Trusts.

The investigation further considers:

- The role of the GP;
- A range of relevant practices, policies, and correspondence templates;
- Relevant stages where patient communication would be expected;
- Patient experiences;
- Accessibility of waiting list information; and
- Planned improvements.

The investigation tests the actions of the Department, and the Trusts, against the framework of the Principles of Good Administration. The Principles of Good Administration are set out in full in **Appendix One**.

The full Terms of Reference can be found in **Appendix Two**.

The Investigative Methodology

During the course of this investigation, evidence was drawn from a wide range of sources using a range of methodologies, including:

- Research and review of all relevant protocols, policies and practices, including all versions of the IEAP;
- Extensive queries and information requests to the Trusts, the Department, and the Strategic Planning and Performance Group (SPPG, formerly the Health and Social Care Board);
- Site visits to each of the Trusts, including meeting with staff from the booking offices and a variety of medical specialties;
- Meetings with the Waiting List Management Unit (WLMU) and the Encompass team;
- Meetings with the Patient and Client Council (PCC);
- Examination of previous NIPSO waiting list complaints and investigations;

- A General Public online survey. The survey ran from 19 May 2022 to 29 July 2022 with 646 responses (blank copy provided in **Appendix Three**). Information was also accepted via submission where requested;[21]
- A General Practitioner (GP) online survey. The survey ran from 9 June 2022 and closed on 12 August 2022 with 321 respondents (Copy provided in **Appendix Four**);
- Follow up interviews with a number of General Public and GP survey respondents who opted into further contact; and
- Case Study reviews - individual cases were identified from previous complaints received by NIPSO and from responses to the General Public survey. Additional patient information requests were made to the Trusts and, where necessary, the individual's GP. The same case study participants are at times used as examples within multiple chapters as an illustration of the multiple issues faced by patients.

I am satisfied that the evidence gathered in this investigation provided a strong understanding of the issue and is sufficient to make a determination as to whether or not maladministration has occurred on a repeated basis.

21 Although 646 respondents completed the survey, individuals were only required to answer questions applicable to them. Therefore, percentages throughout the report are based on the numbers who completed the question/statement being discussed.

Chapter One

The Role of the General Practitioner

"It puts us in a compromised position with pts [patients] as well. Given we have no control over the waiting lists we should not be involved in the communication around them."

GP

"I phone the hospital myself as well as routinely asking my GP if anything else can be done."

Patient

"Requested an update via the Trust but have had no contact from the Trust in 4 years and the person who I spoke to in the consultants office informed me that they could not provide any information and to contact my GP."

Patient

"We are already overwhelmed by repeat patient contacts due to long waiting lists. We do not have the capacity to pass on information about wait times which could be directly passed on to the patient by the trust."

GP

"It has to be the Trust, if it was the GP then that would be yet another layer and delay added to the communication. GP surgeries would be absolutely overwhelmed with queries from the thousands of people on waiting lists wanting to know where they were on the lists. That would be an impossible amount of admin for already over-stretched GP surgeries."

Patient

"The information about waiting lists should be wholly the responsibility of the Trust."

GP

"It is completely unreasonable to expect the GP to be used as a go between giving information on hospital waiting lists."

Patient

"It's not easy and I appreciate the Trust have their own difficulties. I think the only thing we'll ever change, if we're one single organisation. If we depend on them and they depend on us. We need to have a shared aim, and I'm not so sure that happens."

GP

"Because the poor souls are so over stretched its not for them to deal with this."

Patient

"Erratic and infrequent formal communication. Information is poor in frequency, accuracy and accessibility for patients and clinicians alike."

GP

"Waiting list information is not a contractual obligation and should never become a GP's responsibility."

GP

"Very difficult as a GP to have any form of regular update regards waiting list - we do get occasional emails but its not robust."

GP

"It is not our job to provide this information. Once we have referred the patient to secondary care it should be their responsibility..."

GP

"Despite all the years of working across boundaries and interface, it's still in many ways a fractured service."

GP

"Waiting list information seems to come about largely by word of mouth."

GP

"With no knowledge of wait times they [Patients] often become angry and frustrated with us."

GP

"I have contacted the hospital/ Trust secretary directly. I see absolutely no point contacting my GP to do this as they will only have to contact the hospital themselves, leading to unnecessary time wasting."

Patient

"I wouldn't even dream of asking my GP about that, they are so busy."

Patient

"I only provide general waiting time information at the point of referral."

GP

"While some Health and Social Care Trusts provide waiting list information to GP practices this again is not standardised across the region in terms of frequency or presentation."

Royal College of General Practitioners Northern Ireland

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Chapter One

The Role of the General Practitioner

This chapter discusses the expectations placed on General Practitioners (GPs) to provide waiting list communications, and their agreed responsibilities.

Trusts: Expected GP role

As the provider of services, and the administrators of waiting lists, the Trusts have a central role in the provision of waiting list information to patients.

It is therefore of note that within their responses to the investigation the Trusts often deflected from their role, inferring on multiple occasions, that GPs may provide this function:

a. Waiting time reports & the point of initial referral

As part of the investigation's initial enquiries, Trusts were asked if they provided waiting list communications to patients. All Trusts provided the same statement in response:

> *'[X Trust] do not communicate with individual patients regarding waiting times or positions, however we regularly issue waiting time updates for GP colleagues.'*

The investigation team sought clarification to determine whether the Trusts were inferring that by providing information to GPs, this indirectly provides patients with information. In response, some Trusts suggested that they merely considered that GPs '*may*' share the information, while other Trusts confirmed:

> *'We provide GPs waiting list information so that they can inform patients at point of referral'*
>
> *Southern Trust*

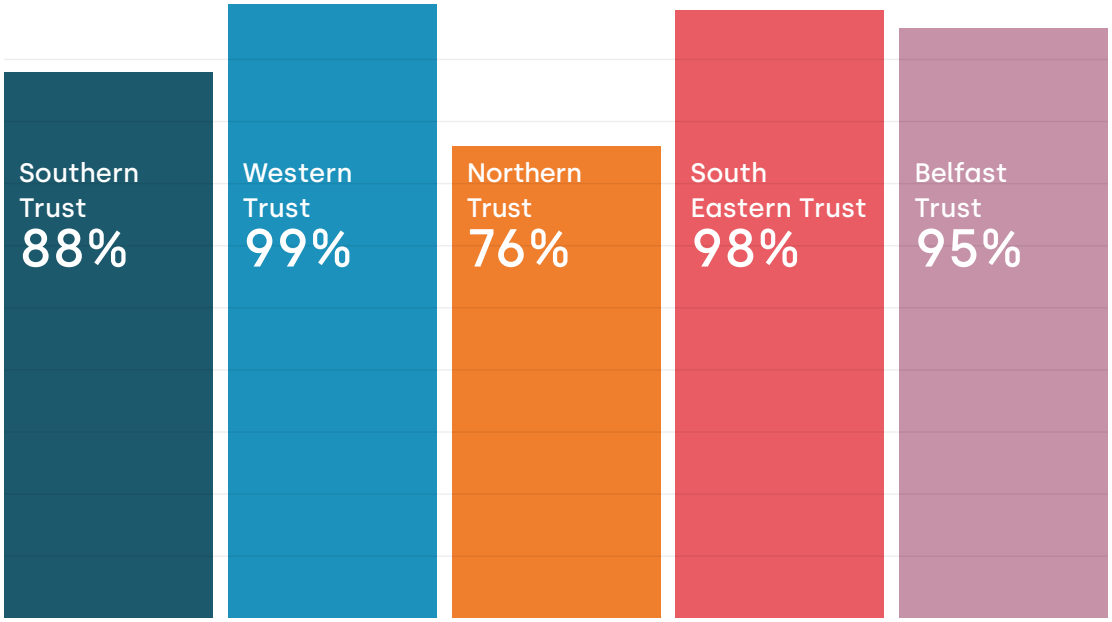
> *'The Trust, via Elective Care Reform lead, provides Trust Waiting times by speciality to GPs. If GPs, choose to share this information with their patients that is within their gift. We would assume GPs do this.'*
>
> *South Eastern Trust*

Given this expectation, it is encouraging that the majority[22] of respondents to our General Practitioner survey, accepted that their role includes provision of general waiting time information to patients - at the point they are referring them to a Trust.

However, GPs highlighted that the Trusts fail to effectively provide them with waiting list information, which subsequently impacts on their ability to undertake this role:

22 79% of GP respondents

*Figure 1.3: The percentage of GP respondents who consider that Trust (waiting list) communication with their practice is **not effective**:*



The investigation's review of the provision of waiting time reports to GPs also identified significant variation in:

Frequency - Some Trusts advised the investigation that they provide the report monthly, others quarterly or 3 times a year.

Distribution - Some Trusts advised that they provide the report directly to GPs, while others provide it through partnerships, or merely 'make it accessible to the GP' by placing it within their website.

Continued provision – Many Trusts ceased publication of the report during COVID -19. While some Trusts reinstated the practice, others did not. Most Trusts also indicated they intend/or have ceased reporting as a result of the Waiting List Management Unit (WLMU) taking over this responsibility (refer to **Chapter Nine: Planned Improvements** for further detail).

This lack of effective communication, and variation in approach, has clearly contributed to the difficulties felt by GPs, and their ability to play an effective role in providing waiting list information at the point of referral.

b. Clinic letters

Clinic letters are a summary of a health professionals' consultation with a patient. Once typed, these letters are typically sent to the patient's GP following the appointment (refer to **Chapter Seven: Clinic Letters** for further detail).

All Trusts, with the exception of Belfast[23], advised the investigation that it is **not** policy to provide clinic letters to patients, unless indicated by the health professional.

23 Refer to Chapter Seven: Clinic Letters – Belfast Trust changed its practice to ensure both patients and GPs are provided with a copy of dictated letters.

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Within their responses, the Trusts again deferred to GPs, advising of their expectation that GPs will communicate information held within the clinic letter directly to the patient, if necessary:

'If the letter is sent solely to the GP, does the Trust expect that the GP will update the patient?'

Response:

'The Trust does expect that the GP will update the patient'

Southern Trust

'Yes if the patient needs to be updated'

South Eastern Trust

'Yes'

Western Trust

'Yes but the patient will have been at an outpatient appointment and will have been spoken to in person by the clinician. If any results are outstanding the patient will be advised of the results by the consultant via letter or at the next review appointment'

Northern Trust

In contrast to providing waiting time information at the point of referral, the GPs who were interviewed as part of the investigation, voiced their concern at the suggestion that they would routinely update patients on clinic letter contents, and made it clear that this was not within their role:

'I don't know how that would be considered reasonable. On any day we receive in excess of 60 or maybe 80 letters, and I don't know how we could make 80 patient contacts every single day to inform patients of a consultation that they've had with a consultant... I think that's absolutely ludicrous...'

GP

'Again, that's me doing secondary care's work and that's you bunging up my phone lines for explaining stuff that I haven't done. If secondary care have done a test then what's to stop them copying that letter to the patient, the same letter? It might be slightly different language saying, "Your CT scan's okay therefore we do not need to see you again." You know, if a patient phones me up and asks me to explain what's on the letter I'd happily do that, of course, but you're making me do what years ago would have been outpatient work. And we're not funded, we're not staffed, you know, I have my own stuff to do.'

GP

'It really is laughable the number of letters...If there's a notion that you'd inform everybody of the content of those letters... If the Trust are going to write something, let them take ownership of it. We wouldn't be a mailing service or an advice line for them. They can't even staff their own advice lines. It doesn't surprise me that they would want us to do that.'

GP

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c. Referrals

Once a referral for a patient is sent to the Trust, it is reviewed or '*triaged*' by a health professional in order to determine an appropriate Clinical Urgency, for example routine, urgent or red flag. Trusts do not, as standard, advise patients of the outcome of this review/triage (Refer to **Chapter Three: Acknowledgements** and **Chapter Four: Triage of Referrals** for further detail).

In response to investigative enquiries, some Trusts referred to the ability of GPs to check whether a patient's referral has been received by the Trust, and to review the outcome. For example:

'Use of CCG [Clinical Communication Gateway] will inform this.'

South Eastern Trust

'GPs are able to view confirmation of receipt on the CCG electronic referral system'

Northern Trust

It was further noted that the Department also referred to a GP's ability to review referral outcomes within a response to a case study participant:

'In relation to your query pertaining to the downgrading of referrals, GPs are able to view on the Northern Ireland Electronic Care Record (NIECR) system the priority outcome after the referral has been triaged by the relevant Trust clinician. GPs are therefore able to confirm if a referral has been downgraded.'

Response to Case Study G

Whilst it is acknowledged that this information is available on Northern Ireland Electronic Care Record (NIECR) and accessible to GPs - this system is not as widely used amongst GPs as the Clinical Communication Gateway.

The CCG typically used by GPs, enables a GP to see if a referral has been **read** – the CCG does not provide confirmation of outcome, i.e., what Clinical Urgency has been applied to a referral after it has been triaged.

This presents several issues as it not only creates an inequality in the accessibility of information, it also places a further burden on GPs' limited resources:

'It would take quite a lot of time and administrative effort to select a patient and go to the referral to see if it's been read. Information available this way is very limited. We don't know if "read" means accepted, or anything at all. Complete lack of clarity.'

'Honestly, if someone thinks we have the time to indulge in this level of scrutiny they should come and sit in a practice for a day or two. Not a chance.'

'I do not have time to do this as a GP - I send on CCG and it is responsibility of the Trust to follow on from there.'

'With such a vast workload it would be physically impossible to keep track and go into each patient's CCG to see if a referral has been seen.'

Extracts taken from the General Practitioner Survey

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GP: Accepted Role

The variation between GP acceptance of what is within their role, and what the Trusts expect of GPs, led my investigation to query with the Department, and the Royal College of General Practitioners Northern Ireland (RCGPNI), whether GPs have an agreed or contractual responsibility to provide waiting list information to patients. Both confirmed they do not:

'In terms of your specific question in relation to whether General Practitioners (GPs) have a responsibility or role to provide waiting list communications to their patients in lieu of the Trusts, ***I can confirm that they do not.***[24]

Department of Health

'It is our firm view that responsibility for this communication does not sit with GPs and practice teams. This would not be feasible in practical terms given the huge capacity challenges within general practice, and the complexity across the five different Health and Social Care Trusts... GPs will continue to provide patients with as much information as they have access to at the point of referral. Following referral, however, we believe that there must be clear lines of communication and the responsibility for providing this important information to patients should rest solely with Health and Social Care Trusts.' [25]

Royal College of General Practitioners Northern Ireland

It is also of note, that patient expectation of the GP's role in providing waiting list information varies significantly from that of the Trusts, with 95% of our General Public survey respondents indicating that it is the Trust who should provide regular updates directly to patients, or to both the patient and their GP.

Less than 4% of respondents indicated that updates should regularly be provided to the GP, who can then update the patient.

24 Extract from former Permanent Secretary of the Department of Health's response to Notification of Investigation, dated 22 March 2022
25 Extract from Royal College of General Practitioners Northern Ireland response to NIPSO, dated 22 February 2022

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Impact

GPs expressed concern, both within our GP survey and during interview, about the expectation placed upon them in relation to the provision of waiting list information.

> *'This places an unnecessary additional burden on GP workload- putting pressure on staff/telephone lines/ GP time when the communication should be between patient and hospital.'*
>
> *GP*

Although the majority of GP respondents accepted that they have a limited role (at the point of referral), they identified that patients continue to contact the practice beyond this point.

GPs, who engaged with the investigation, suggested that this was in part due to Trust booking offices and Consultant Secretaries failing to manage patient expectations. They advised that Trust staff often redirect patients back to their GP, either to seek updates – which the GP cannot provide, or to request additional referrals – which may not be clinically required.

> *'The reception is inundated with calls about referrals - it is a VERY COMMON occurrence and stops other patients accessing our telephone lines. It is very common that either hospital booking services, or Consultant secretaries re-direct patients to their GP about waiting times for referrals- even though they are fully aware we have no control over them!'*
>
> *GP*

GPs[26] felt this placed a significant strain on GP resources. Many also raised that it can lead to further distress to the patient, and potential tension in the GP/patient relationship:

> *'Frustration is directed at primary care team, both at admin staff and GPs, for a system we have no involvement with or influence over.'*
>
> *GP*

26 94% of GP respondents identified that providing waiting list information to patients places a significant strain on their resources.

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Chapter One 'The Role of General Practitioners' Findings

Being Customer Focused

Maladministration - The Trusts' failure to facilitate good communication with patients; and its failure to engage with GPs and agree a clear policy in relation to sharing waiting list information with patients.

The second Principle of Good Administration states that public bodies must ensure that people can access services easily and respond to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

It is acknowledged that with the right information, GPs accept that they can play a role in sharing waiting list information, usually at the point of referral. However, the Trusts' failure to provide timely and consistent waiting list information to GPs has meant that GPs are unable to facilitate this role effectively.[27]

Furthermore, the Trusts' reliance on GPs to provide waiting list information outside of this stage of referral, is inappropriate. GPs do not have a contractual obligation to provide this information and are often not in possession of timely, accurate information as the Trust has not shared it. The lack of a clear policy in relation to this practice means that Trusts are assuming that GPs will share waiting list information with patients rather than providing the information directly to patients.

In doing so Trusts are failing to facilitate good communication with patients. Adding an additional layer to the distribution of information, removes any suggestion of a '*patient centred*' focus and leads to potential confusion as to whom patients should be contacting for updates.

Recommendation 1

1.1 The Department and Trusts should engage with GPs, and their representative bodies, on a wide scale in order to discuss the provision of waiting list information to patients. This engagement/consultation should include:

- Discussion on what waiting list information GPs expect/require from the Trusts to ensure appropriate management of patient care;
- An agreed approach to the stages in which a GP is likely, or best able, to provide information to patients; and
- An agreed approach to Trust communications with patients in regard to requesting repeat referrals.

1.2 The Department should revise the IEAP in line with the consultation, and issue guidance to ensure this approach is followed by all Trusts.

1.3 The Department should take sufficient steps to ensure GP Practices are aware of the 'My Waiting Times NI' website.

27 The Department have recently launched the 'My Waiting Times NI' website, which is accessible to both GPs and patients (refer to Chapter Nine: Planned Improvements)

Chapter Two

IEAP: Protocol vs Reality

"I never heard a word in 5 years until I had to go back to my doctor in severe pain."

Patient

"I have had no contact from anybody in the NHS...I believe they think I have died."

Patient

"I have only received one letter which was 3 years after my referral asking if I wanted to stay on the waiting list. Apart from this I have had no communication what so ever."

Patient

"...info is vague and needs to be a monthly update to GP practices and patients."

GP

"There is an obligation & a duty of care by the health department to engage, be transparent & to provide up to date data, that keeps patients informed. Presently there is zero communication delivered."

Patient

"Within the Trust you will have thirty different ways of doing the same job across different departments because they're so fragmented and silo'd within their own system."

GP

"I had no communication at all and had to seek it out myself. Any communication would have helped."

Patient

"We have never been informed re this [IEAP]. Never heard of it????"

GP

"I have received no communication at all for a number of years."

Patient

"'Never heard of the IEAP."

GP

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Chapter Two: Integrated Elective Access Protocol

This chapter focuses on the Protocol which Trusts are expected to follow when managing waiting lists.

Focus on Patient Communication

In 2006 the Department of Health (the Department) first published written waiting list management/booking guidance for the Trusts, entitled the *'Integrated Elective Access Protocol'* (IEAP). Updated versions were subsequently published in 2008 and 2021[28].

The IEAP states that its purpose is:

> *'To advise and inform patients and clinical, administrative, and managerial staff of the approved processes for managing patient's access to outpatient, diagnostic, elective and elective Allied Health Professional (AHP) services.'*
>
> *IEAP June 2020*

The Department additionally highlights the IEAP's focus on patient communication:

> *'A key theme throughout the document is the importance of ensuring prompt, timely, and accurate communication with patients as a core responsibility of the hospital and the wider local health community.'*
>
> *Department response to NIPSO, 22 November 2021*

> *'The IEAP provides guidance on how Trusts should communicate with patients as part of the booking processes.'*
>
> *Department response to NIPSO, 1 July 2022*

Although all Trusts agree that they manage their waiting lists in line with the IEAP, their response to NIPSO appeared to contradict the Department's responses, stating:

> *'Each Trust manages their waiting lists in line with the current Integrated Elective Access Protocol which sets out the approved procedures for managing elective referrals to first definitive treatment or discharge, **however this protocol does not provide procedures for communication with patients**.'*

In considering this disparity, I reviewed all versions of the IEAP and identified that all make statements, or directions, in relation to patient communication at various stages of the waiting list process, including for example:

28 Version dated June 2020 was not published or shared with the Trusts for implementation until December 2021

'5.3.5 Following prioritisation, referrals must be actioned on PAS or the relevant electronic patient administration system and appropriate correspondence (including electronic), ***e.g. Acknowledgement or appointment letter, issued to patients within one working day.'***

'5.6.5 Virtual review appointments, e.g. telephone or video link, should be partially booked. If the patient cannot be contacted for their virtual review they should be sent a ***partial booking letter*** *to arrange an appointment.'*

'3.9.1 DNAs – Diagnostic Appointment If a patient DNAs their diagnostic appointment the following process must be followed: 3.9.1(a) Patients who have been partially booked will not be offered a second appointment and should be removed from the waiting list. ***The patient and referring clinician (and the patient's GP, where they are not the referring clinician) will be informed that, as they have failed to attend their appointment, they have been discharged from the waiting list.'***

Extracts taken from IEAP June 2020

Whilst it is noted that IEAP patient communication directions are at times scant and sporadic, with no clear '*start to finish*' communication process, it is evident that a certain level of direction has been provided. I therefore found it concerning that many of the respondents to our General Public survey indicated that they had received no communication (refer to quotes within the **Chapter cover page**).

In response to my identification of this issue the Department raised concern:

'We think this misinterprets the purpose of IEAP. The primary purpose of the IEAP is to detail how Trust staff should manage the booking and scheduling of patients waiting for an assessment, diagnostic test or treatment. This includes communicating with patients as part of the booking/scheduling process. The purpose of document was not to provide guidance on how waiting time information should be communicated throughout the patient journey.'

Department response to the draft investigation report 25 April 2023

I do not consider that the sole purpose of the IEAP is to provide guidance on how waiting time information should be communicated. Nor do I consider that current Trust communications solely lack waiting time information. The chapters within this report illustrate how this forms only part of the deficiencies identified during my investigation.

However, as the Department and the IEAP state, the importance of patient communication is a key theme of the document, as evidenced by the directions that are in place. The IEAP is also the only Department document available to Trusts which provides any guidance on expected waiting list patient communication. I would therefore expect the IEAP to have clear, consistent, and complete communication directions.

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General Practitioner Awareness

As discussed in more detail in **Chapter One 'The Role of General Practitioners' Findings**, it is accepted by the Trusts and the Department that it is not the responsibility of GPs to provide waiting list information to patients. However, I recognise the importance of health professionals (such as GPs), who refer patients to or within the Trust, being aware of waiting list processes, particularly as they are likely to be the first interface a patient may have in relation to placement on a waiting list.

This integrated role is highlighted within the IEAP:

> *'1.1.2 … General Practitioners (GPs), commissioners, hospital medical staff, allied health professionals, managers and clerical staff have an important role in ensuring access for patients in line with maximum waiting time targets as defined in the Department of Health (DOH) Commissioning Plan Direction (CPD) and good clinical practice, managing waiting lists effectively, treating patients and delivering a high quality, efficient and responsive service. Ensuring prompt timely and accurate communication with patients is a core responsibility of the hospital and the wider local health community.'*
>
> *IEAP June 2020*

I therefore found it surprising that 95% of respondents to our GP survey advised they were not familiar with the IEAP.

This lack of awareness was highlighted to the Department, and a query was raised whether it considered that GPs should have an awareness of the IEAP. In its response, the Department advised:

> *'Yes. However it is clear that refresher training is required.'*

I further queried with the Department what level of GP engagement it had undertaken in relation to the latest IEAP:

> *'Can the Department advise whether GPs were consulted on the draft and updated IEAP? If yes can the Department advise how and when this was shared?'*

Response:

> *'Dr X was part of the IEAP review group and [they] provided a GP perspective…'*

It is concerning that the Department would suggest that this limited level of engagement, with one GP, is appropriate. This has almost certainly contributed to an overall lack of awareness of the IEAP amongst General Practitioners.

Update and Review

At the time of my initial review of Waiting List Communications as a potential issue in 2021, I was concerned to note that the last published IEAP was dated 2008, particularly as this same version stated:

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'1.1.4 This protocol will be updated, as a minimum, on an annual basis to ensure that Trusts' policies and procedures remain up to date and reflect best practice locally and nationally.'

IEAP 2008

I raised my concerns with the Department, who advised:

'...work is underway to update the Integrated Elective Access Protocol (IEAP) with a draft version dated June 2020 available...'

22 November 2021

Following commencement of my investigation, in April 2022, I requested an update on progression of the draft. The Department advised that it had been formally issued to the Trusts, by the Health and Social Care Board (HSCB now SPPG) on 8 December 2021, just weeks after its response to my initial queries. The cover letter that went to the Trusts with the IEAP stated:

'You will be aware of the work that had been undertaken to revise the 2008 IEAP which concluded in June 2020. The Department has considered the revised document and notes the changes...I would appreciate if you could circulate within your respective Trusts for implementation and to note the protocol will be uploaded to the Departmental website.'

8 December 2021

I was surprised to note that this letter referred to the revision of the IEAP being concluded in June 2020, given that the Department had advised my office that work was currently '*underway*', over a year after this suggested conclusion date.

I was also concerned that the IEAP, which is available to the public on the Department's website[29], retains the date of June 2020, when it was not shared with the Trusts for implementation until December 2021. There is also no reference to this issue date within the approval section of the IEAP. Many of these sections remain blank.

Document:	Integrated Elective Access Protocol 3.0
Department:	Department of Health
Purpose:	To advise and inform patients and clinical, administrative and managerial staff of the approved processes for managing patients access to outpatient, diagnostic, elective and elective Allied Health Professional (AHP) services.
For use by:	All clinical, administrative and managerial staff who are responsible for managing referrals, appointments and elective admissions.
This document is compliant with:	Northern Ireland Health and Social Care (NI HSCC) and Department of Health (DOH) Information Standards and Guidance and Systems Technical Guidance. https://hscb.sharepoint.hscni.net/sites/pmsi/isdq/SitePages/Home.aspx
Screened by:	
Issue date:	
Approval by:	
Approval date:	
Distribution:	Trust Chief Executives, Directors of Planning and Performance, Directors of Acute Care, Department of Health.
Review date:	June 2022

I acknowledge the Department's reasoning that these sections were not completed as a result of the redeployment of staff following Covid. However, I am concerned that this is yet to be remedied[30].

I am also concerned to note a lack of update to corresponding appendices. For example, Appendix 4[31], which is published on the Department's website alongside the 2020 IEAP, and is published as '*Appendix xx*', makes an outdated reference to sections held within the 2008 IEAP:

29 Last checked 22 March 2023
30 Last checked 9 February 2023
31 Appendix 4 Implementation Procedure for DNAs and Cancellations (health-ni.gov.uk)

'There are a number of guiding principles in the management of the patients who DNA/CNA appointments. These are detailed in Section 3, paragraph 3.8 of the Integrated Elective Access Protocol.'

Appendix 4 'IMPLEMENTATION PROCEDURE FOR PATIENTS WHO CANCEL OR DO NOT ATTEND'

Section 3 paragraph 3.8 of the 2008 IEAP was entitled:

'3 .8 MANAGEMENT OF PATIENTS WHO CANCELLED (CNA) OR DID NOT ATTEND (DNA) THEIR APPOINTMENT'

However, paragraph 3.8 of the 2020 IEAP is entitled:

'3.8 PATIENTS LISTED FOR MORE THAN ONE DIAGNOSTIC TEST'

Appendix 4 also contains guidance which conflicts with the main body of the 2020 IEAP. Advice suggests that, following the cancellation of an appointment by a patient, they should be referred back to their GP. However, the main body of the 2020 IEAP repeatedly advises that the patient, as well as the GP, should be informed.

This apparent lack of due care and attention in the update to the IEAP is heightened in the knowledge that the Department had already failed to review the IEAP between 2009 – 2020. The Department's reasoning for this failure was that experience from previous reviews '*found that an annual update was not required as the policies and procedures remained consistent with good practice*'. They further advised that it was for this reason that the IEAP, dated June 2020, states that the document will be reviewed '*regularly*'.

Given that waiting times accelerated considerably during this period, I remain unconvinced by the argument that update and review against local and national good practice was not required. I do not accept that 11 years is a reasonable period of '*regular*' review.

Staff sign off

In considering the importance of this document, and the expectation that it is implemented across all Trusts, I noted that all versions of the IEAP state:

*'**All** staff involved in the administration of waiting lists will be expected to read and **Sign off this protocol.'***

However, when asked to provide evidence of recent staff sign off, the Trusts advised that this action is not undertaken:

'Trust staff do not formally sign off IEAP... Records of induction and training are retained locally within services'

Northern Trust

'IEAP training is part of induction and is available on Trust intranet and shared drives. Trust staff do not formally sign off IEAP'

South Eastern Trust

'Read but no sign off.'

Southern Trust

'Trust staff do not formally sign off IEAP. Guidance relating to IEAP is provided to relevant staff. The Trust also provides training for staff.'

Belfast Trust

'IEAP is an integral part of staff induction and ongoing development and is readily available for local access... staff are not routinely required to sign off that it has been read.'

Western Trust

I am concerned that this published IEAP direction is not followed.

There is no indication from the Trusts or the Department that this non-compliance has ever been formally discussed, or that an agreement was reached that this was no longer required. Indeed, the continued placement of this direction within the current IEAP suggests that the Department consider it to be a necessary step.

This non-compliance was queried with the Department who responded:

'The Department was not aware that there was non-compliance. For example, in the Western Trust, all new staff are trained on the IEAP during induction and there is ongoing training / updates when new guidance is issued. Staff are asked to sign off on their understanding of the protocol and any new guidance issued. There is also monthly validation carried out by all team leads to ensure adherence to the IEAP. Currently all staff should be issued with the Trust guidance and also attend IEAP training.'

Non-compliance: Governance of the IEAP

The failure of the Department and the Trusts to follow longstanding directions within the IEAP, raised concerns in relation to how compliance is monitored and addressed.

Following review of the IEAP, and correspondence from the Department and the Strategic Planning and Performance Group (SPPG), it became apparent that there is a lack of clarity in relation to where this responsibility lies, particularly in regard to patient communication.

Although, most recently, it has been suggested that the Waiting List Management Unit (WLMU) will '*have a role to play*' in compliance, the responses provided to my office indicate that directions on patient communication are not currently monitored.

'Monitoring compliance with the processes in this document should be part of Trusts internal audit processes.'

IEAP June 2020

'Going forward, the new Waiting List Management Unit will have a role to play in performance management of Trust implementation of this policy, and will undertake (when necessary) site visits or audits to ensure compliance.'

Department Letter, Nov 2021

'Can the Department advise whether they review Trust compliance with the IEAP's requirements in regards to notifications to GPs and Patients? Can supporting evidence be provided?'

Response: *'The Department does not review Trust compliance with the IEAP requirement in regards to notifications to GPs and patients. The need to maintain patient confidentiality and limit access to patient level data would make this difficult to monitor. SPPG (previously HSCB) has never had access to patient level data nor would it be appropriate for staff outside of Trusts to be given access to this level of information. While SPPG cannot access patient level data it can track individual anonymized patients which enables the analysis and monitoring of waiting times.'*

Department response to NIPSO July 2022

'a. Can the WLMU advise whether any failure to adhere to the IEAP in relation to waiting list communications has been identified?'

Response: *'The WLMU is currently reviewing adherence to IEAP, but it should be noted that the focus of IEAP is about booking processes rather than waiting list communication.'*

'b. If yes can the WLMU advise what action is being taken?'

Response: *'[Blank]...'* *WLMU response to NIPSO Nov 2022*

It is noted that the Department raised the issue of patient confidentiality in relation to monitoring communications. There is no suggestion that, compliance should routinely monitor patient communication on an individual, un-anonymised, level, but instead focus on whether or not the communications aspects of the IEAP have been delivered (e.g., that Acknowledgement letters are being sent to patients).

If monitoring does not take place, it is unclear how the Department can be confident that the actions laid out within the IEAP are undertaken across all Trusts.

IEAP Review Group

The identified non-compliance raised further concerns in relation to the Trusts' awareness of the detail of the Protocol, and their opportunity to raise concerns with implementation.

I note that the IEAP review group participants are listed within the published 2020 version of the Protocol. The group was predominately[32] made up of Trust Staff, with each of the five Trusts having had at least one representative.

With the knowledge that some IEAP directions have not been followed, I would expect that if the Trusts have difficulty in implementing certain directions, or if they dispute that they are required, this review group would have been the forum within which these concerns should have been discussed.

The records shared with us suggest that none of the above issues were raised by the Review Group, and therefore the review group's sign off on the 2020 version may be considered approval of the directions.

32 8 of the 11 group members are Trust staff

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However, it is of note that during the investigation I identified a misplaced understanding that the Trusts can decide whether or not they follow the IEAP. This position was identified following review of an individual complaint case, where the South Eastern Trust had advised that it was **not Trust policy** to send Acknowledgements. Our Office sought clarification:

'In response (27 September 2021) to NIPSO queries [Chief Executive] advised 'Mr X did not receive Acknowledgement of his referrals as it is not Trust policy.' Can the Trust provide comment on why they consider that the IEAP is not Trust policy?'

Response: *'IEAP is a protocol not policy and therefore Trust decision.'*
South Eastern Trust

This was raised with the Department who responded:

'b. Do the Department consider that as the IEAP is a Protocol it is the Trusts decision whether or not they apply it?'

Response: *'Trusts are expected to implement the policies and processes detailed in the document.'*

Whilst the South Eastern Trust's misplaced view does not appear to be held by other Trusts, it may be an indicator of a general lack of regard for the IEAP's application, which has been heightened by the lack of compliance monitoring and the Department's failure to regularly review and update the IEAP.

Chapter Two 'IEAP' Findings

Getting it Right

Maladministration – Trusts' non-compliance with directions set out in the IEAP.

The first Principle of Good Administration requires public bodies to '*Get it Right*' by taking account of established quality standards and good practice, and acting in accordance with the public body's policy and guidance (published or internal).

As highlighted within this chapter, directions set out within the IEAP, such as the requirement to review and update annually, have not been met. I am concerned that, for this reason, there has been a missed opportunity to take into account UK good practice in waiting list communications, for a considerable period of time (2009-2020).

Further evidence of non-compliance with the IEAP will be discussed within subsequent chapters of the report.

Being Customer Focused

Maladministration – through a lack of detailed direction in the IEAP the Department fails to provide clarity and reassurance for patients.

The second Principle of Good Administration states that public bodies should provide clear, understandable policies and procedures, informing customers what they can expect.

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The IEAP itself refers to its purpose being to inform patients of the approved processes for managing waiting lists. A patient reading the IEAP may be informed, and potentially reassured, that certain practices take place, when in reality, this investigation has identified several areas where directions are not followed and compliance is not monitored. In addition, I am concerned that the patient communication directions contained within the IEAP are sporadic, with a lack of detail on what information should be provided to patients.

Be Open and Accountable

Maladministration – lack of transparency around the publication of the IEAP.

The third Principle of Good Administration requires that public bodies should be transparent, open and truthful. Providing clear, accurate and complete advice. I am concerned that the Department failed to take reasonable steps to raise an awareness of the IEAP to GPs and considered one GP on the review group sufficient engagement. This may be considered a missed opportunity to fully inform health professionals, who have a role in referring individuals, of the expected processes. However, I welcome that the Department has since recognised the need for refresher training.

I am also disappointed that the most recent IEAP was published with a date of June 2020, even though the date of issue to the Trusts was December 2021. From June 2020 to December 2021, the 2008 IEAP would have been applicable.

Putting things Right and Seeking Continuous Improvement

Maladministration – Department's failure to review and update the IEAP and monitor compliance.

The fifth and sixth Principles of Good Administration require that public bodies review policies and procedures regularly to ensure they are effective, seek continuous improvement, and put mistakes right quickly and effectively. My investigation has identified that the IEAP went through a significant period whereby no review or updates were undertaken, during which time significant non-compliance has gone unremedied.

Recommendation 2

2.1 The Department should review and amend the IEAP. The review should include:

- Consideration of all recommendations made within this report;
- Consultation with all Trusts and General Practitioner representatives to ensure agreement, understanding and standardisation of approach;
- An outline of how compliance with the IEAP (including communication) will be monitored, and how non-compliance should be reported; and
- A regular interval review requirement to ensure that the significant lapse in update does not reoccur.

2.2 The Department should change the date of the 2020 IEAP to reflect the date of implementation.

2.3 The Department should engage with GP representatives to discuss how best to engage with primary care to ensure increased IEAP awareness and provision of training. Subsequent evidence of this engagement, and the facilitation of training should be collated and provided to NIPSO.

2.4 All Trusts should place a copy of the IEAP within the recommended dedicated 'Waiting list Information section' of their website (*refer to* **Recommendation 8**).

I note that in response to my draft report the Department has committed to reviewing the IEAP every 2 years.

Chapter Three

Acknowledgements: What is needed?

"I think the example set by some specialities of a standard letter to patient confirming placement on waiting list, contact info if situation changed and interim signposting should be the very basic standard. Included in this letter should also be an explanation of the average waiting time in the previous quarter for a patient to that specialty for that grade of appointment, obviously with a proviso that it's average and can change. Patients deserve to know these basic facts..."

GP

"Letter to give patient estimated waiting time for their appointment once referral has been triaged would be helpful. They can then decide if going privately is a better option for them at this stage..."

GP

"I think patients should know what waiting times are as it is, in my opinion, the thing affecting access to care the most."

GP

"Trust/department contact details as it is nigh on impossible to find the correct department /person to speak to."

Patient

"As a minimum an update that A. You are on a list. B. Expected time frame. C. Outline process when referral to another Trust will be necessary..."

Patient

"If the initial letter had informed me of current waiting times I would not have had to phone up and give more work to already busy staff."

Patient

"A letter of acknowledgment of the referral and a letter once it was triaged to tell us if it was done as routine or urgent and to let us know the wait times would have been very helpful."

Patient

"Good communication is key... A letter to say we have received your referral, the likely wait is x and here is who you contact if your condition changes/ deteriorates."

Patient

"An acknowledgement from the Trust that the referral has been received. Category of waiting list priority. Expected time frame for appointment Name of assigned Consultant."

Patient

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Chapter Three: Acknowledgements

This chapter focuses on the communications provided to patients once a referral is received by the Trust.

What should happen?

Once a request (referral) for assessment or treatment is received by the relevant medical specialty within a Trust, it is expected, in accordance with the Integrated Elective Access Protocol (IEAP), that the Trust will inform the patient.

Examples of IEAP extracts referring to Acknowledgements to patients:

IEAP 2006:

'2.5.2 Acknowledgement letters will be sent to the patient within five days of receipt of the referral. The estimated length of wait will be indicated on the acknowledgement letter.'

IEAP 2008:

'3.5.3 Acknowledgement letters will be sent to routine patients within five days of receipt of the referral. The estimated length of wait, along with information on how the patient will be booked, should be included on the acknowledgement letter.'

IEAP 2020:

'2.3.5 Following prioritisation, referrals must be actioned on PAS and appropriate correspondence (including electronic), e.g. acknowledgement or appointment letter, issued to patients within one working day.'

Our investigation identified significant non-compliance with this direction across the Trusts, with many medical specialties having discontinued Acknowledgements for significant periods of time. This was reflected within the responses to our General Public survey, where 83% of respondents stated that they had not received any waiting list communication, other than an invitation to make a booking/appointment.

Although it is recognised that some Trusts/specialties have reintroduced various forms of Acknowledgement in recent years, it is of note that several identified no intent to commence, or reinstate, this practice:

'The main booking office has acknowledged referrals to patients since 2019. Several smaller specialities also acknowledge referrals to patients, however a large number do not.'

Northern Trust

'We introduced acknowledgement letters in and around 2007. We ceased sending these letters in February 2014.'

South Eastern Trust

'The Trust ceased sending acknowledgement letters to patients at a date prior to 2010. We cannot provide a definitive chronology, acknowledgements have not been sent since the decision to cease this process.'

Western Trust

'The Trust ceased sending acknowledgement letters to patients when waiting times were reduced during 2015/16, as there was potential for acknowledgement letters and appointment letters to arrive simultaneously. These acknowledgement letters were reinstated in February 2019 when waiting times began to increase. ..Radiology do not send out acknowledgements to patients... Community Paediatrics - Acknowledgement to patients regarding receipt of referral and adding to waiting list is due to commence in September 2022.'

Southern Trust

'The Trust sends an acknowledgement text or letter (if mobile n/a) to patients who have been added to the Hospital Outpatient Waiting List on the Patient Administration System [PAS] to advise that their OP [Outpatient] referral has been received and they will be contacted when an appointment is available. This currently excludes Radiology, AHP [Allied Health Professional], Orthopaedics and Oncology OP referrals at present, however the Trust is currently reviewing if arrangements to implement referral acknowledgement for AHP, Orthopaedics and Oncology can be introduced. Gender Identity patients are written to, to confirm they have been added to the WL[Waiting List]. Radiology are currently reviewing this under the implementation of a regional Single Radiology System...'

Belfast Trust

I am concerned that, although the Department confirmed that Trusts had *'verbally raised concerns'* with the resources required to undertake Acknowledgements, no evidence could be provided to indicate that the decision to cease Acknowledgements was ever formally discussed or agreed. There is also no evidence to suggest that the Department has taken any action to address this issue.

I was also concerned that the Trusts future computer system, Encompass (which will be discussed further in **Chapter Nine: Planned Improvements**), does not currently have the facility to send an acknowledgement:

'...We don't make any contact with the patient (like a letter, etc.) until we hit scheduling such as a partial booking letter or appointment reminder letter... This request has not been raised so far during workflow design.'

Encompass PMO

However, I am pleased to note that following my draft report being shared with the Department they have confirmed that functionality for an acknowledgement will be sought.

Where Acknowledgements do take place, what do they look like?

'While we recognise the immense pressures across our health service, we consider that the communications provided by Health and Social Care Trusts to patients on waiting lists to be inadequate. The current approach differs significantly across all five Health and Social Care Trusts and is not consistent.'

Royal College of General Practitioners Northern Ireland

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As highlighted within the Trust response extracts, if a patient is referred to Western or South Eastern Trust it is **unlikely** they will receive an Acknowledgement. The first waiting list correspondence they are likely to receive is a booking/appointment letter – which will be provided approximately 6 weeks prior to an expected appointment. This raises the credible prospect that many[33] patients will wait a year, or more, to receive any confirmation that they have been added to a waiting list.

In contrast, if a patient is referred to Northern, Belfast or Southern Trust, they **are likely**[34] to receive an Acknowledgement. However, the method in which an Acknowledgement is sent, and the level of information provided, may differ significantly.

For example, some Trust medical specialties send an Acknowledgement text message – typically through an external provider:

> *'Belfast Trust has received a referral letter for you for an outpatient appointment. You have been added to the outpatient waiting list. We will contact you approx 6 weeks before your appointment is due. For enquiries, if your contact details have changed, or you have been seen by another hospital please call…'*
>
> *Example - Belfast Trust text message content*

Other medical specialties send a standard Booking Office Acknowledgement letter, accessible within the Trusts' main computer booking systems:

Belfast Health and Social Care Trust

Private & Confidential

[Hospital Address 1]
[Hospital Address 2]
[Hospital Address 3]
[Hospital Address 4]
[Postcode]

[TITLE] [Surname]
[Address line 1]
[Address line 2]
[Address line 3]
[Address line 4]
[Postcode]

Date
Patient Ref No. [ref number]
H&C Number [H&C number]

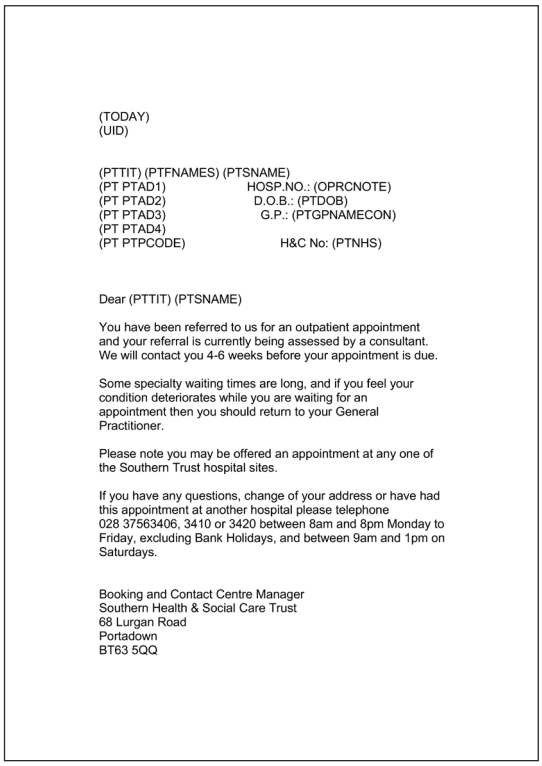
Dear [Patient Full Name]

You have been referred to us for a [SPECIALITY] Outpatient Appointment. Your referral letter has been triaged by the consultant and you have been added to the Outpatient Waiting List.

We will contact you approximately 6 weeks before your appointment is due.

If you have any queries, you change your address or have been seen at another hospital, please telephone our Appointments Helpline on [SITE TEL NUMBER] between [SITE OPENING HOURS].

Appointments Manager



(TODAY)
(UID)

(PTTIT) (PTFNAMES) (PTSNAME)
(PT PTAD1) HOSP.NO.: (OPRCNOTE)
(PT PTAD2) D.O.B.: (PTDOB)
(PT PTAD3) G.P.: (PTGPNAMECON)
(PT PTAD4)
(PT PTPCODE) H&C No: (PTNHS)

Dear (PTTIT) (PTSNAME)

You have been referred to us for an outpatient appointment and your referral is currently being assessed by a consultant. We will contact you 4-6 weeks before your appointment is due.

Some specialty waiting times are long, and if you feel your condition deteriorates while you are waiting for an appointment then you should return to your General Practitioner.

Please note you may be offered an appointment at any one of the Southern Trust hospital sites.

If you have any questions, change of your address or have had this appointment at another hospital please telephone 028 37563406, 3410 or 3420 between 8am and 8pm Monday to Friday, excluding Bank Holidays, and between 9am and 1pm on Saturdays.

Booking and Contact Centre Manager
Southern Health & Social Care Trust
68 Lurgan Road
Portadown
BT63 5QQ

33 As of 30th September 2022, over half (189,437) of patients waiting for a first outpatient appointment, and 55% (68,565) of patients waiting for an inpatient or day case admission, had been waiting for over 52 weeks; Northern Ireland Waiting Times Statistics: Inpatient Waiting Times Quarter Ending September 2022 (nisra.gov.uk)

34 Exceptions based on medical specialty

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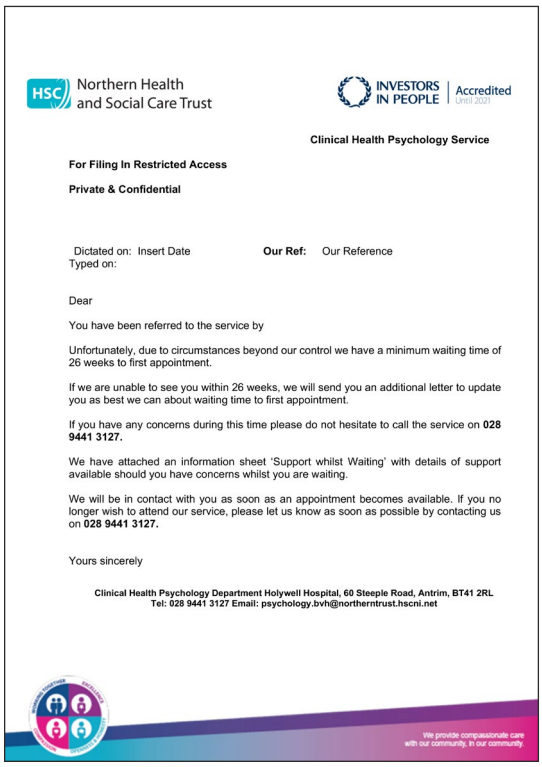
A limited number of medical specialties have also developed their own Acknowledgement template:



Northern Health and Social Care Trust

INVESTORS IN PEOPLE | Accredited Until 2021

Clinical Health Psychology Service

For Filing In Restricted Access

Private & Confidential

Dictated on: Insert Date **Our Ref:** Our Reference
Typed on:

Dear

You have been referred to the service by

Unfortunately, due to circumstances beyond our control we have a minimum waiting time of 26 weeks to first appointment.

If we are unable to see you within 26 weeks, we will send you an additional letter to update you as best we can about waiting time to first appointment.

If you have any concerns during this time please do not hesitate to call the service on **028 9441 3127.**

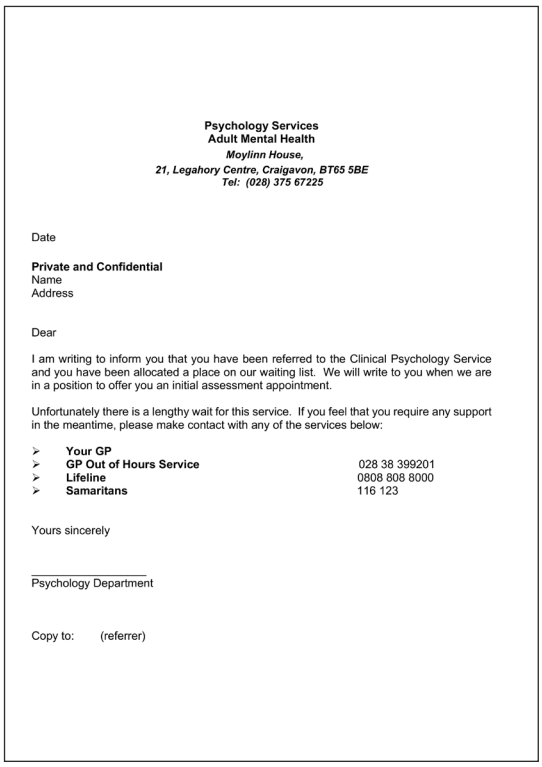
We have attached an information sheet 'Support whilst Waiting' with details of support available should you have concerns whilst you are waiting.

We will be in contact with you as soon as an appointment becomes available. If you no longer wish to attend our service, please let us know as soon as possible by contacting us on **028 9441 3127.**

Yours sincerely

Clinical Health Psychology Department Holywell Hospital, 60 Steeple Road, Antrim, BT41 2RL
Tel: 028 9441 3127 Email: psychology.bvh@northerntrust.hscni.net

We provide compassionate care with our community, in our community.



Psychology Services
Adult Mental Health
Moylinn House,
21, Legahory Centre, Craigavon, BT65 5BE
Tel: (028) 375 67225

Date

Private and Confidential
Name
Address

Dear

I am writing to inform you that you have been referred to the Clinical Psychology Service and you have been allocated a place on our waiting list. We will write to you when we are in a position to offer you an initial assessment appointment.

Unfortunately there is a lengthy wait for this service. If you feel that you require any support in the meantime, please make contact with any of the services below:

- **Your GP**
- **GP Out of Hours Service** 028 38 399201
- **Lifeline** 0808 808 8000
- **Samaritans** 116 123

Yours sincerely

Psychology Department

Copy to: (referrer)

This variation in format frequently impacts on the level of information provided to patients.

Text message Acknowledgements are often limited to confirming:

- receipt of referral;
- provision of a general contact number; and
- identification that further correspondence will be sent 6 weeks prior to an appointment.

Template letters typically provide additional information, such as confirmation of specialty and reference to consultant review of the referral.

Bespoke Acknowledgements usually go further, providing advice on seeking additional support, and referring to extended waiting times.

Despite the above evidence suggesting that additional information can, and sometimes will be provided, our General Public Survey suggests that this is the exception rather than the rule, with only a limited number of patients identifying that they had received additional information over and above the level found within a text message Acknowledgement:

Figure 3.1: Percentage of positive responses to the question 'If you received waiting list communications, did one or more contain the following:'

Advice on when to expect updates	Support/ Signposting information	Advice on what to do if condition changes	Average wait times
2%	7%	9%	4%

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Why should Acknowledgements happen?

'It is our view that all patients deserve clear communication as to their position on a waiting list and we would welcome efforts to improve this lack of consistency and ensure standardisation of information to all patients...A regular reminder of place on a waiting list would not only afford patients the update but act as a timely reminder and opportunity to communicate any personal changes. Improving this communication could also enable transparency regarding patients sitting on several different lists.'

Royal College of General Practitioners Northern Ireland

'We need to have an honest conversation with patients. They deserve to know when to expect their surgery, how long they will wait and what they can do to "wait well"'[35]

Royal College of Surgeons England

It is clear, from the Department's IEAP direction to Trusts, that it recognises the value in communicating with patients at the outset of their waiting list journey. However, as Acknowledgements frequently contain a limited level of information, and as there is no guarantee they will be sent, patients and their families are often negatively impacted.

Respondents to our General Practitioner survey provided substantial comment based on their experience, alongside individual case examples of patient impact, including:

'It is truly awful for patients at the minute. Their condition has been considered serious enough to require specialist input but they have no idea how long they will be waiting for assessment or treatment. Some put off doing other things in case they miss an appointment. People have no control over this process and this can have a very negative effect on mental health.'

'..the psychology of waiting is very well researched and waiting without knowledge of the potential wait is hugely detrimental to patient well being..'

'[A] Referral to Cardiothoracics [was] declined but not communicated to GP or patient. 1 year later patient called to check on wait list and [was] informed referral [had been] declined. Only then was the e-triage information copied to the GP. Patient's referral wait time unnecessarily extended by 1 year due to lack of communication.'

'Patient referred via CCG [Clinical Communication Gateway] and after 18 months still no acknowledgement from hospital /contacted surgery and staff rang hospital to check and advised no referral had been received - audit trail showed it had been seen and printed at hospital end.'

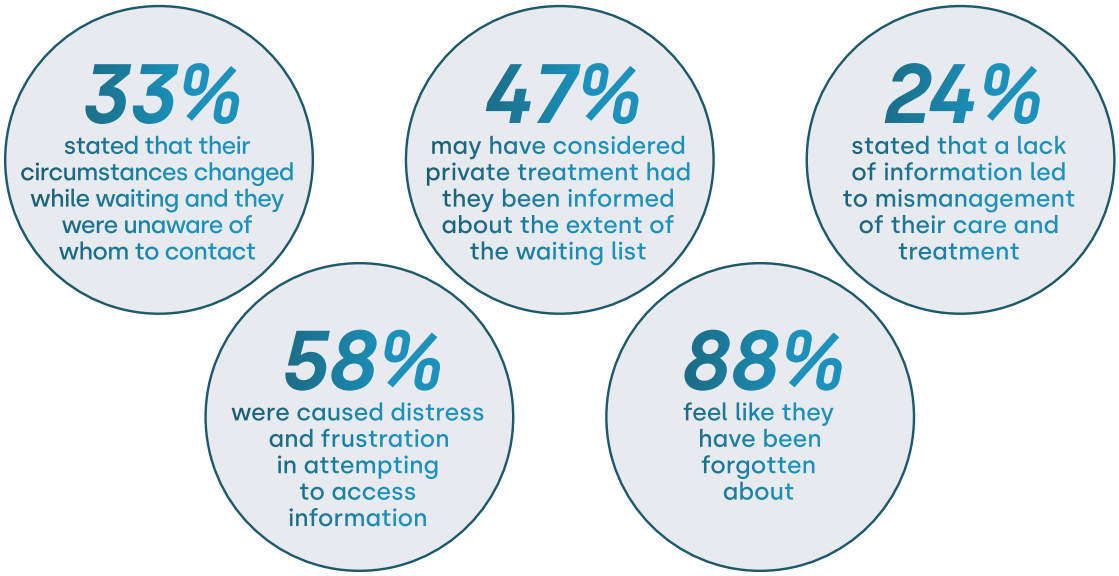
'Sent a red flag CCG referral, when it was uploaded the content didn't upload, so patient was discharged. No communication back...'

Quotes taken from NIPSO GP Survey

Our General Public survey identified that 92% of respondents also reported a negative impact. This ranged from patients/carers identifying that they were unable to take actions/decisions as they remain uninformed, to those who identified significant effects on their health and well being:

35 Extract from Royal College of Surgeons of England in Northern Ireland response to NIPSO April 2022

Figure 3.2: Negative impact on patients based upon responses to General Public survey



The individual cases reviewed as part of the investigation identified similar or additional issues to those highlighted, including:

- Uncertainty whether a referral had been sent or received;
- Error in follow up/placement on a waiting list – leading to significant delay;
- Duplication of placement on a waiting list;
- Additional pressures on GP resources to provide information/follow up or repeat referrals;
- Reliance on the persistence of individuals to seek out waiting list information for themselves – creating an inequality to those who are potentially not equipped to do so;
- Uncertainty of the medical specialty an Acknowledgement relates to – particularly where individuals have multiple conditions; and
- Significant impact on well being, with the patient/their family suffering distress, anxiety, and frustration.

These issues are illustrated within the following case studies:

Case Study 1
Issue: Lack of Acknowledgement contributed to family attributing a failure to GP

Trust: Southern Trust
Medical Specialty: Dermatology

In February 2019 Patient A attended their GP practice due to a growth on the right side of their nose. The GP subsequently sent a '*Routine*' referral, dated 12 February 2019, to the Trust's Dermatology Department. The referral was reviewed electronically and e-triaged on 15 February 2019. A screenshot of the e-triage outcome suggests that Patient A was subsequently added to the waiting list on 17 February 2019.

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The Trust did not send an Acknowledgement to Patient A. No information was provided to confirm:

- the patient's clinical urgency;
- average waiting time;
- placement on the list;
- what to expect; or
- contact details should more information be required.

Patient A's symptoms continued to worsen and, following no communication from the Trust, they again attended their GP Practice on 22 February and 29 April 2019. It was noted within GP consultation records that they *'awaited dermatology'*, and further treatments were prescribed.

Following a subsequent attendance to the GP practice on 28 September 2019 and a record of deterioration, a further referral, marked 'Urgent', was sent to Dermatology.

A biopsy was taken at the end of October 2019. Two weeks later, the patient received a diagnosis of Squamous Cell Carcinoma of the nose and commenced radiotherapy shortly thereafter. Unfortunately, following a period of illness,
Patient A passed away in March 2021.

Patient A's family subsequently raised a complaint with the GP Practice and this Office. Included within their complaint was their mistaken concern that the GP practice had not sent a referral until September 2019:

'AUGUST 2019 CONSULTATION WITH DR [x]

[Patient A], increasingly concerned that the growth was spreading and frustrated with no further investigation, referral to a dermatologist or action from the Practice (other than prescribing antibiotics which clearly were not working), on [their] own initiative, contacted the relevant booking office to arrange an appointment with a dermatologist. I stress this was on [Patient A's] own initiative and NOT the Practice. On the advice of the booking office [Patient A] contacted the next available GP, in this case [Dr X] who wrote a letter of referral to the booking office.'

Impact

This case highlights the potential issues which can arise through a lack of communication/Acknowledgement.

The Trust's failure to send an Acknowledgement following receipt of the GP's referral in February, led to the family's initial belief that the GP had not sent any referral until September 2019.

Although this was not the sole aspect of the family's complaint, this lack of confirmation undoubtedly contributed to Patient A's, and their family's, anxiety in relation to the management of their cancer diagnosis.

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Case Study 2
Issue: Lack of Acknowledgement resulting in prolonged period of distress

Trust: South Eastern Trust
Medical Specialty: Audiology/Ear Nose Throat Department

On 30 September 2018 Patient B attended their GP, who subsequently sent a referral to the Trust's ENT [Ear Nose and Throat] Department. The referral was received by the Trust and graded as the Clinical Urgency '*Routine*'. The Trust did not send an Acknowledgement to Patient B to advise that the referral had been received. No information was provided to confirm:

- the patient's clinical urgency;
- average waiting time;
- placement on the list;
- what to expect; or
- contact details should more information be required.

Over 2 and a half years later, following no communication from the Trust, Patient B again attended their GP, resulting in an '*Urgent*' referral being sent on 22 May 2021. Again, no communication was sent to Patient B to confirm that their referral had been received, or the outcome of their referral.

Patient B complained to the Trust, their MP, and subsequently NIPSO, about the lack of communication:

'I first went to my local GP... in September 2018. My GP referred me... on that day. Since then I have heard nothing. Not a phone call. Not a letter. Nothing. I am still waiting for any information on how my medical treatment will proceed 2 years and 7 months later.'

In response the Trust advised that Patient B did not receive an Acknowledgement as '*it is not Trust policy*'. It further stated that

'The Trust does not have the capacity to action the additional administrative work that would be involved in acknowledging all the referrals received.'

Impact

This case highlights a number of issues which can arise from a lack of communication/Acknowledgement including the considerable distress, frustration and uncertainty that can arise.

It also raises the concerning viewpoint of the South Eastern Trust that *'it is not Trust policy'* to provide Acknowledgements, despite the IEAP retaining a longstanding direction to do so.

Personal Reflection:

'If it were not for me initiating this complaints procedure I am unsure if I would ever have heard from them'

Patient B

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Case Study 3
Issue: Lack of Acknowledgement resulting in duplication

Trust: Western Trust
Medical Specialty: General Surgery (gall bladder)

Following a series of review appointments over a period of several years, Patient C attended their GP who re-referred them to the Surgical team on 7 September 2015 for reassessment for gallbladder surgery.

The Trust did not send an Acknowledgement to Patient C to confirm their referral had been received.

Patient C subsequently attended a Surgical Clinic on 30 March 2016 (2 years and 2 months since their last review). They were reviewed by a Consultant General Surgeon and placed on a waiting list for surgery.

Following placement on the list the Trust did not send an Acknowledgement. No information was provided to confirm:

- the patient's clinical urgency;
- average waiting time;
- placement on the list;
- what to expect; or
- contact details should more information be required.

However, almost 2 months after the consultation, a Clinic letter was sent to the Patient's GP dated 12 May 2016, which stated:

'...[They] have been seen by Mr [X] who has advised that [they] be placed on the waiting list for a laparoscopic cholecystectomy. [Their] name has been placed on the waiting list for laparoscopic cholecystectomy.'

A copy of this letter was not sent to the patient.

14 months after the consultation, following no communication to the patient, Patient C advised they contacted their GP to request a further referral. They subsequently attended a further Clinic with a different consultant on 11 May 2017.

The Clinic letter, sent to the GP following this consultation, stated:

'...I have sent [them] an appointment at the Pre-assessment Clinic and have placed [their] name on the waiting list for an urgent laparoscopic cholecystectomy..'

This letter was not sent to the patient.

Again, no Acknowledgement was sent to the patient to confirm that they had been added to a waiting list. This duplicate waiting list error was left unremedied.

In July 2017 Patient C received their operation. However almost a year later, (as they remained on a second waiting list) they received an invitation to attend a surgical clinic appointment. Patient C advised that it was only when they attended that it was discovered that this appointment had been arranged to assess them for the surgery they had already underwent:

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'Dr [X] referred to an email from management at the Trust to say that I was on the waiting list for too long and needed to sort this out...I was completely flabbergasted when Dr [X] proceeded to say that I would be sent to have surgery within the following week to remove my gallbladder because of the waiting list I was on for too long. I told Dr[X] I had my gallbladder removed in July 2017 to which Dr [X] responded "Are you sure?"...'

In response to this Office the Trust apologised to the patient 'for this administrative error.'

Impact

This case highlights significant concerns resulting from a lack of communication with patients. As Patient C received no Acknowledgement, or copy of a clinic letter[36], to confirm they had been added to a waiting list, they were faced with uncertainty in relation to progress of their care/treatment. This led to significant distress and frustration.

It is likely, that had an Acknowledgement been sent, Patient C would have been clear as to their waiting list status and their expectations could have been managed appropriately.

In addition, had the Trust actioned a practice of Acknowledgements, the error of being placed on two separate lists, for the same procedure, would have been identified at a much earlier stage – potentially limiting the unnecessary expenditure of resources.

Personal Reflection:

'... failed to provide a sufficient system of the arrangement of medical appointments, referrals and over all failed to provide sufficient customer service for patients...'

Patient C

36 Refer also to Chapter Seven: Clinic Letters

Case Study 4
Issue: Lack of communication led to Patient's belief they were on waiting list for surgery for 6 years, when this was not the case

Trust: Belfast Trust
Medical Specialty: Ear Nose Throat Department

In 2013, as part of a waiting list initiative, Patient D was seen by an ENT Consultant within a private clinic. Following a consultation in August 2013, the Consultant advised Patient D that they required surgery. The Clinic letter, sent to the Patient's GP, dated 12 August 2013, stated:

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'... This [patient] is a candidate for a septorhinoplasty operation. [They] need to be seen pre-operatively to discuss the procedure risks and benefits.'

Patient D believed that from this point they had been added to the Waiting List for surgery.

On 16 November 2013, the Trust sent a letter to the Patient, and their GP, advising that the private clinic could no longer provide arrangements for the patient's ongoing care and treatment and that they would be returning to the Trust. They further stated:

'..The clinical notes related to your patient's care and treatment by [the private clinic] are being provided to the Belfast Trust. The Trust will then make contact with your patient as soon as possible to advise them of ongoing care and treatment arrangements.'

The private clinic notes, which included the Clinic letters identifying the consideration and requirement for surgery, were received by the Trust.

No communication was provided to the patient to acknowledge that they had been added to the Trust waiting list for surgery, or that their medical notes had been received.

During subsequent years, Patient D continued to attend the Trust's ENT department in relation to other conditions, continuing to believe that they were awaiting surgery:

'...I have tinnitus and I had a branchial cyst on my neck and a good lot of times I was given hospital letters where I was going and I didn't know what I was going there for, whether it was my nose, my neck or my ears... There was no clear indication on the letters when you have an appointment. So, that's ENT, because every one of my problems was ENT related, you know, my neck, my nose and my ears. So, I used to go, "What am I here for?...'

In September 2017, 4 years since the Patient was first informed they required surgery, the patient's GP sent a referral to the ENT Department which records:

'Previously seen at [Private clinic] diagnosed as needing septoplasty but was lost to follow up I would be grateful for reassessment? Surgery.'

The letter is date stamped by the Trust with '*routine*' noted. Patient D was added to the routine assessment list on 17 September 2017.

The Trust sent no Acknowledgement to Patient D to advise that the referral had been received. No information was provided to confirm:

- the patient's clinical urgency;
- average waiting time;
- placement on the list;
- what to expect; or
- contact details should more information be required.

As no communication was received from the Trust, the patient's GP sent a subsequent Urgent referral in April 2018, attaching the 2013 private clinic letter. The referral stated:

'Previously seen by ENT and told needs septorhinoplasty 2013 – has not heard back since. Referred urgently in view of delay.'

This letter is date stamped by the Trust with '*routine*' triage noted.

Again, no Acknowledgement was sent to the patient.

In April 2019, almost 6 years since first being assessed as requiring surgery, and 18 months since the patient's GP sent a referral querying the surgery, Patient D was reviewed and added to the surgery waiting list. The Consultant ENT Surgeon Clinic letter stated:

'Patient was lost to follow up having been seen in [private clinic]. [they] were awaiting septorhinoplasty and dorsal hump reduction... Plan: 1) Discussion of options, risks and benefits, 2) Addition to waiting list for septorhinoplasty and dorsal hump reduction 3) will be sent for in due course.'

Patient D subsequently made a complaint to the Trust in November 2020 stating:

'I wish to make a complaint in relation to the length of time it has taken for me to receive the surgery I require. I understand with the current COVID 19 pandemic things have been put on hold but my case has been going on long before COVID19...'

In its response, dated 16 January 2021, the Trust advised:

'...Unfortunately, the ENT medical staff who reviewed you between 2010 and 2019 were not aware that you had nasal issues and their efforts were regarding the lump in your neck, your hearing loss and your tinnitus...There is no record of the Belfast Trust receiving a copy of [Private Clinic Consultant's] letter prior to the referral received from your GP. I am extremely sorry for the inconvenience and distress this has caused you...'

Impact

This case identifies a number of issues with the communications provided to patients on waiting lists.

It is noted that in 2013 the Trust advised the patient, and their GP, that it was being provided with the clinic notes from the Private Clinic. These notes were evidenced within the file provided to this Office by the Trust and contained the Private Clinic Consultant's letter. It is therefore concerning that the Trust later advised the patient, and NIPSO, that it was unaware of the assessment of the need for surgery until the letter was sent by the GP within the 2018 referral.

It is also unclear why the Trust did not act upon receipt of the clinic notes – as suggested within its 2013 letter – and why it did not communicate with the patient once these were received to advise them of ongoing care and treatment arrangements.

The mismanagement in this case, where a patient became '*lost to follow up*' for almost 6 years, highlights the need for Trusts to put in place an appropriate Acknowledgement and regular update procedure for those added to waiting lists. If patients came to expect these communications, they would then be in a position to query what action has been taken if they do not receive a communication, reducing the opportunity for these issues to arise.

Personal reflection:

'I would expect a letter for sure, anybody would expect a letter to know what's happening next. It's always best to be kept in the loop, not just to go, you need this done, right, sure we'll be in touch whenever we feel like it, you know... see even to get a letter saying we do apologise but we're going to have to knock you back another year. At least you know where you stand, you know, you're not like always guessing.'

Patient D

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I am considerably concerned by both the accounts provided to my office through our surveys, and the cases reviewed. The impact of no, or limited, communication whilst on a waiting list should not be underestimated.

What should Acknowledgements look like?

Given the increasing waiting lists across the UK, good communication to patients has become even more relevant, with NHS England recently publishing a '*Good Communication with patients waiting for care*' [37] guide in 2021. This guidance highlights that communications:

> *'... should give clarity on the next steps of a patient's care pathway including likely and honest timescales, and what they can expect... If a patient is going to experience a long delay, open and honest communications will help manage expectations. This should be supported by a realistic timescale as to when the patient can expect to hear further information. If next steps are uncertain, explain that to the patient... consider providing patients with additional information or signposting them to resources that will help...'*

Although it is accepted that this guide was written for acute Trusts in England, it is of note that much of the recommended content has been identified to be currently lacking in Northern Ireland.

Our General Public survey identified that 90% of respondents consider that the communications provided to patients on waiting lists needs to be improved. This was supported by our GP survey where 96% of GPs went as far as to suggest that major improvements are required.

79% of General Public respondents suggested that the first communication (the Acknowledgement) should contain all of the following:

- Confirmation of the date added to the waiting list;
- Position on the waiting list;
- Average waiting times;
- Anticipated timeframe for appointment;
- Clinical Urgency;
- Contact details to access updates and advise of changes in circumstances;
- Advice on when to expect updates;
- Advice on what to do if their condition changes;
- Advice on what to do if they are unable to attend;
- A request to identify availability for cancellation/short notice appointments;
- Information on how to request the communication in a different format; and
- Supporting information to help manage their condition while waiting.

The majority of respondents also indicated that they would prefer to receive this information via letter or email[38], with just under half[39] indicating text message as an accepted format of communication.

I am therefore concerned by the level of information absent from Acknowledgements, which patients rightly consider should be provided as standard.

37 Briefing template (england.nhs.uk) Good Communication with patients waiting for Care 25 May 2021
38 73% indicated letter as a preferred method; 69% indicated email
39 48%

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Chapter Three 'Acknowledgements' Findings

Getting it Right & Acting fairly and proportionately

Maladministration – Trusts' failure to provide Acknowledgements in a consistent manner, across all specialties in line with the IEAP.

The first Principle of Good Administration requires public bodies to '*Get it Right*' by taking account of established quality standards and good practice. The fourth principle of Good Administration requires that public bodies deal with people fairly and consistently.

As previously highlighted, the IEAP sets out the requirement to send Acknowledgements, but this is not delivered across all Trusts as standard, resulting in negative impact for some patients. The variation in provision of Acknowledgements creates inequality for patients - a patient may be better informed on their waiting list status, dependent on which Trust and medical specialty they are referred to.

Being Customer Focused

Maladministration – The IEAP fails to provide appropriate guidance in relation to what information should be held within an Acknowledgement.

The second Principle of Good Administration states that public bodies should provide understandable policies and procedures, allowing service users to be clear about what they can and cannot expect from the public body.

The IEAP does not provide sufficient clarity and reassurance for patients despite highlighting the importance of prompt, timely and accurate communication within the protocol.

In response to this finding of maladministration the Department advised:

'We believe this is wrong. The IEAP appendices include a New Routine Acknowledgement template letter which details the information which should be provided to patients as part of the acknowledgement process.'

The current IEAP – which the Trusts are currently expected to follow – does not hold an acknowledgement template. The appendix the Department refer to was a partial booking acknowledgement letter which was attached to the **2006** IEAP. It does not feature in the revised 2020 IEAP, nor is there any reference or link to the template. The 2006 IEAP is also no longer available to the public as only the 2020 version is published on the Department website.

The 2006 partial booking acknowledgement template did contain clinical urgency alongside the expected waiting time. However, this template was put in place when the main body of the IEAP retained a communication direction that estimated length of wait should be provided to patients within an acknowledgement. This has since been removed and does not feature in the 2020 IEAP.

The next Chapter in this report also outlines how the 2008 direction to include outcome of triage within patient communication no longer features within the

2020 IEAP. It is therefore unsurprising that 17 years on, the current partial booking template, which is featured earlier within this chapter, does not contain this information.

I am therefore concerned that the Department consider that this finding is wrong based on a template which does not cover all specialties (not all specialties follow partial booking processes); is no longer referenced within the current 2020 IEAP and which does not correlate with the revisions made to the main body of the IEAP. It remains the case that the current IEAP fails to provide appropriate guidance in relation to what information should be held within an acknowledgement.

Be Open and Accountable

Maladministration – Trusts' failure to provide a meaningful standard of content in Acknowledgements (when these are issued).

The third Principle of Good Administration requires that public bodies should be transparent, open and truthful, ensuring that any advice provided is clear, accurate and complete.

This investigation has identified that Acknowledgements/advice provided to patients is not complete. Patients are either not provided with an Acknowledgement, or are not provided with content that would be expected by the general public and best practice. This can result in mismanagement in a patient's care and treatment and lead to significant patient distress, anxiety and frustration for prolonged periods of time.

I welcome that at the outset of my investigation all Trusts accepted the need for a standardised approach, and regionally agreed waiting list template. I also recognise and commend the limited number of specialties who have attempted to provide an additional level of information, over and above what has been accepted practice by the Department and the Trusts.

Putting things Right

Maladministration – Department and Trusts' failure to address or rectify non compliance of Acknowledgements.

The fifth Principle of Good Administration requires that public bodies put mistakes right quickly and effectively.

Although both the Department and the Trusts are aware of the significant level of non-compliance with the IEAP, they have not taken appropriate steps to ensure Acknowledgements are reinstated in full.

I note that in response to this finding the Department advised:

'This understates the work being done in this area. The Department have been working with the Text Messaging provider to support Trusts in the implementation of text messages in relation to the acknowledgement of referral letters. Costings have been received from the provider and discussions are taking place to secure the associated funding.'

I welcome the recent review of acknowledgement communications and the advisement that functionality for an acknowledgement will be placed within Encompass. I look forward to receiving confirmation that text messaging acknowledgements, with an appropriate level of information, have been put in place across all Trusts and specialties. However, I remain concerned that non-compliance was ongoing for a significant period of time with no apparent action being taken.

Recommendation 3

3.1 The Department and the Trusts should review the survey data provided within this report, alongside the good practice guidance available across the UK, and put in place a standard waiting list Acknowledgement template. As a minimum this Acknowledgement should identify:

- receipt of referral;
- the specific medical specialty within which the referral has been received;
- the patient's Clinical Urgency and whether this has changed;
- average/expected waiting time and a link to the anticipated Waiting List Management Unit (WLMU) waiting times website (refer to **Chapter Nine: Planned Improvements** for further detail);
- what to expect; and
- details on who to contact should more information be required.

Moving forward, this template should be included within the Encompass system.

3.2 Where a patient is waiting 6 months or more, the Department/Trusts should provide an update. As a minimum, this update should include the average waiting time and details on who to contact should more information be required, or should their circumstances/contact details have changed.

3.3 The Department should revise the IEAP to include these changes. It should also publicise these changes to all potential referrers, inside and outside of the Trusts, with direction to advise patients to expect this Trust communication.

3.4 If the Department/Trusts consider that there should be exceptions to the requirement – for example if an appointment/booking letter is likely to be sent on the same day as an Acknowledgement letter/text - this should be published within the IEAP. Adjustments should also be made to the booking/appointment letter to ensure the additional information provided within an Acknowledgement is still provided. The Department/ Trusts may wish to consider the introduction of a separate 'Waiting list information sheet', which includes the above information, and can be attached to either an Acknowledgement or a booking/ appointment letter.

3.5 The Department and the Trusts should undertake a compliance review, 6 months after the publication of this report, to assess the implementation of this recommendation across all Trusts and medical specialties. Should non-compliance be identified this should be discussed, with actions recorded.

3.6 The Department should consider the inclusion of an acknowledgment flag/reminder or suitable alternative within Encompass. The purpose of this flag would be to indicate to specialties where an Acknowledgement has not been sent within the required timeframe. It may also serve as a compliance tool/indicator for the Department.

In response to my draft report the Department advised that, in light of my recommendation, they have agreed funding to take forward the implementation of a Trust wide text messaging service.

Until this is operational the Department further advised that all Trusts will be required to generate an acknowledgement letter to patients, including the clinical prioritisation, within 3 working days of receipt of referral. This requirement will be clearly stipulated in the IEAP.

I welcome this action and look forward to reviewing the content of the acknowledgement texts to ensure they provide an appropriate level of information. I would also suggest that the Department considers the use of the text messaging service to provide updates to patients waiting longer than 6 months.

Chapter Four

Triage of Referrals: Awareness

"My GP referred me as Urgent twice but the Consultant downgraded my urgent surgery twice without my knowledge, or that of my GP. For months I assumed I was on a waiting list, before meeting the Consultant and told I was not."

Patient

"I just recently found out that my referral was changed several times by the Trust from Urgent to Routine only to be changed back to Urgent again by the Trust....And again this information was only provided by me contacting the booking centre about not receiving any information at all since my 2018 referral."

Patient

"Literally I would have to go searching on CCG [Clinical Communication Gateway] to even see if a referral has been read. Then there is no info on outcome. Only way I know if a pt [patient] has been put on a WL [Waiting List] is when a letter from OPC [Outpatient Clinic] comes back."

GP

"I only found out what clinical status I was placed on when I rang to chase as no word received."

Patient

"CAHMS [Children and Adolescent Mental Health Services] does explain why referrals are rejected, sends us notification referrals have been triaged and justifies referral downgrade or rejection but they truly are the exception. Well done WHSCT [Western Health and Social Care Trust] CAMHS"

GP

"I have had extra delays before from thinking I was on the urgent waiting list only to find out after I should have been seen, that I was mistakenly on routine, and having to phone around to let original referrer know so that they can get it corrected - by which time the urgent wait time starts over again & sometimes is equal to routine - leading to delays in treatment urgently needed."

Patient

"...review was downgraded from urgent to routine without me been informed."

Patient

"Absolutely no information on waiting times, or that my urgent GP referral was downgraded to routine."

Patient

"When I spoke about my condition to a doctor, about 4 months ago. She gave me a number to phone to see what was happening. I was told, "I was not red flagged, only urgent". Therefore I am still waiting on a long list. That was disappointing for me to hear."

Patient

"I had no idea. When you are told your GP is sending an urgent referral you assume they have assessed your condition and feel this is necessary. No explanation as to why this is then downgraded to routine being provided then leaves you worried."

Patient

"I was not made aware I had been accepted onto a waiting list. My referral was considered urgent by my GP, but then assessed by a Consultant and downgraded to routine without my knowledge."

Patient

"GP only informed if patients referral has been 'rejected' or downgraded from red flag to urgent, both of which require additional work for the GP."

GP

"Patient should be informed 'you have been added to waiting list for Dr X your referral has been triaged as routine/urgent/red flag by DrX/Y the current wait time is X weeks and if your condition changes you can update us at the following number."

GP

"Clarity in communications about where they are on a waiting list, what urgency their referral was sent as, what urgency it has been allocated..."

GP

"Notification as to why despite a GP referring as 'urgent' discovering, by my own initiative, and without having had any clinical consultation a Dr at the hospital, decided to place me as 'routine' and consequently being 200 on a list."

Patient

"was told by nurse I was priority but didn't even know that till I had an appointment in Musgrave hospital."

Patient

"... I wasn't aware that I was red flagged on system until a consultant was very cross as this was my second heart attack and he apologised for the system failing me.."

Patient

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Chapter Four: Triage of Referrals

This chapter focuses on the communications provided to patients following the Trust's assessment of referrals.

When completing a request (referral) for assessment or treatment, the health professional making the request (referrer) will indicate what they consider to be the patient's '*Clinical Urgency*' i.e., Routine, Urgent or Red Flag (suspect cancer). Often[40], the referrer will verbally communicate this '*urgency*' to the patient at the time the referral is being sent.

Once a referral is received by the intended medical specialty within a Trust it is then '*triaged*'[41] by a consultant, or other health professional. In some cases, the initial '*Clinical Urgency*' suggested by the referrer will be changed, for example an Urgent referral may be downgraded to Routine. It is this '*triage*' decision which determines which '*Clinical Urgency*' waiting list the patient will be added to.

As already highlighted in **Chapter Two: Integrated Elective Access Protocol**, the Trusts are expected to adhere to the Integrated Elective Access Protocol (IEAP) when managing waiting lists. The current version of the IEAP (June 2020) does not make specific reference to the communication of referral outcomes, however it is noted that the 2008 version included the following stipulation in relation to the management of Integrated Clinical Assessment and Treatment Services (ICATS):

'2.2.3 The outcome of the triage will be confirmed by letters to the GP and patient within a further two working days of triage (five working days in total from receipt).'

The Department were asked why this direction was removed from the IEAP. In response it advised:

'a)…. Section 2.3.5 in the updated document states that "following prioritisation referrals must be actioned on PAS and appropriate correspondence (including electronic) eg acknowledgement or appointment letter issued to patients within one working day'. This would apply to all referrals.

'b) Can the Department provide comment on whether or not it considers that the outcome of referrals (particularly where there is a change) should be provided to patients by the Trusts?'

Response: *See response to point A.*[42]

Although the Department's response is not entirely clear, it is reasonable to read the quoted paragraph as a direction that referral outcomes should be provided to the patient following triage (prioritisation).

40 75% of GP survey respondents confirmed they routinely advise patients what clinical urgency they have placed on the referral
41 Assessed in order to determine the urgency of the required treatment/review
42 Department response dated December 2022

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Despite the IEAP directions, and the comments of the Department, it is of note that the investigation identified wide variation across all Trusts and specialties in relation to the communication of '*Referral Triage*' outcomes. The vast majority of specialties do not communicate any changes directly to patients, while referrers are usually only informed if a Red Flag referral has been downgraded, or a referral has been rejected.

The General Public Survey further identified that 82% of the limited number of respondents who had received a waiting list communication, were not advised of their '*Clinical Urgency*'. While only 10% of the General Practitioner survey respondents identified that they typically receive confirmation of a patient's Clinical Urgency.

This lack of communication can raise significant issues for patients, as illustrated within the following case study examples:

Case Study 5
Issue – Downgrade in Referral – no communication to patient or referrer

Trust: South Eastern Trust
Medical Specialty: Plastic surgery

On 9 December 2017 Patient G, who has profound learning difficulties, complex needs and co-morbidities, attended their GP practice with their family member, to raise an ongoing concern with their condition. The GP advised the family they would send an Urgent referral to the Trust.

The referral was sent to Belfast Trust General Surgery, who redirected it to Plastic Surgery in the South Eastern Trust. This referral was received by the South Eastern Trust on 5 January 2018. Following review of the referral, the triaging consultant downgraded the referral to Routine.

No communication was provided to Patient G and their family, or their GP, to advise that the referral had been received or that it had been downgraded. No information was provided to confirm:

- the patient's clinical urgency;
- average waiting time;
- placement on the list;
- what to expect; or
- contact details should more information be required.

Six months on from the referral being sent, having received no communication from the Trust, Patient G's family member advised they attended the South Eastern Trust Headquarters for an update on Patient G's waiting list status, as they stated they had been *'hitting a brick wall'* when trying to access information through the booking office. It was at this point they were informed that Patient G had been placed on the Routine list and that the waiting time would be 98 weeks.

Patient G's family member contacted their GP to update them on their communications with the Trusts. The GP's notes from the calls record:

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're W/L for general surgery apt- at present autumn 2019 after being redirected to UHD [Ulster Hospital] Plastics'

'Had a chat to parent as [parent] rang BCH [Belfast City Hospital] re apt – told would be 2019 before gets apt! Will see whether Dr [X] can do this …'

Patient G's GP subsequently sent a letter to the Trust to try and expedite the appointment. The request was triaged, with Patient G being upgraded to Urgent on 16 June 2018. Patient G was subsequently seen on 9 July 2018, 5 weeks after the GP sent the expedition letter, and 7 months following the GP's initial Urgent referral.

Impact

This case highlights significant issues resulting from the Trust's lack of communication. Not only did it cause a delay in the patient's review – as it is likely the GP would have expedited the case sooner had the Trust communicated the change at the outset - but it also caused considerable distress, anxiety and frustration to the family when they became aware that Patient G had not been placed on the waiting list they had initially expected.

Personal Reflection:

'The communication between the Trust and ourselves, is extremely inadequate. Between the 1st referral and the letter of complaint there was zero communication from the Trust to any party. It was only when [Patient G's family member] rang to enquire about waiting times that the circumstances surrounding [Patient G's] referral were clarified.'

Patient G's GP

'The downgrading resulted in the waiting time to receive a first out-patient appointment being turned from months to years with [Patient G] having to regularly revisit the GP only to be repeatedly prescribed prophylactic antibiotics (the prescribing GP believing [Patient G] was on an "urgent" waiting list). I subsequently took a major heart attack due to the stress of it all…'

Patient G's Family member

Case Study 6
Issue: Downgrade in Referral – no communication to patient or referrer

Trust: Belfast Trust
Medical Specialty: Orthopaedics

Patient E was suffering from pain in their right shoulder. On 9 September 2016 their GP sent an '*Urgent*' referral to Orthopaedics.

4 days later the referral was triaged by the Trust and downgraded to '*Routine*'. Patient E was subsequently placed on the routine waiting list for assessment.

No standard communication was provided to the GP or the patient to advise that the referral had been downgraded, or to acknowledge that Patient E had been placed on the Routine waiting list. No information was provided to confirm:

- the patient's clinical urgency;
- average waiting time;
- placement on the list;
- what to expect; or
- contact details should more information be required.

However, a validation letter was sent on 1 December 2017, 14 months later, to query if Patient E still required their appointment.

On 1 May 2018, Patient E's GP made a further '*Urgent*' referral. This referral was triaged by the Orthopaedic Service on 20 May 2018 as '*Urgent*'. Patient E was subsequently added to the Urgent list for assessment.

Again, no Acknowledgement was sent to advise the GP or patient that the patient's referral had been received, or that they had been added to the Urgent waiting list.

Approximately 8 weeks later, on 12 July 2018, Patient E was seen by a Consultant Orthopaedic surgeon. Within this consultation the patient was advised that surgery would be inappropriate/would not work. Patient E complained to the Trust as they were concerned that the delay in being seen had resulted in their unsuitability for surgery. They subsequently brought their complaint to NIPSO.

As part of the NIPSO investigation independent professional advice (IPA) was sought from a Consultant Orthopaedic Surgeon. In relation to the reasonableness of the downgrade, the IPA advised:

'... In my opinion, this should have been treated as a more urgent case rather than routine, in order to decide whether the rotator cuff was going to be repairable at that stage... They should have been reviewed earlier and perhaps had an MRI scan to assess whether the tendon was repairable, although I admit that despite this, it may not have been possible to repair the rotator cuff tear.'

The Trust also advised within the investigation that in March 2019, the waiting time for a '*Routine*' shoulder appointment was in the region of **128 weeks**, whereas an Urgent appointment was between **6-8 weeks**.

Impact

This case identifies significant issues resulting from a lack of Trust communication. Had the initial downgrade been communicated to the patient and the GP at the outset, the GP may have sent additional information/ requested expedition earlier; the patient's 22 month wait for assessment may have been significantly reduced; and, although uncertain, the repair of the rotator cuff tendons **may** have been possible at that point.

Regardless of potential outcome, had the patient been seen sooner it is likely they would not have suffered the distress, and frustration of not knowing whether their wait was the cause.

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Case Study 7
Issue: Triage outcome not communicated

Trust: Belfast Trust
Medical Specialty: Orthopaedic Surgery

Patient H was assessed by an orthopaedic specialist and added to a routine waiting list for right total hip replacement on 21 July 2017.

On 22 July 2017 Patient H's GP sent an Urgent referral to the Trust to recommend that consideration should be given to upgrading the urgency of the patient's surgery:
'I feel that this is an urgent case which needs to be expedited... there is a serious risk of irreversible deterioration in this patient's physical and mental health, which could be prevented by them having a hip replacement and appropriate rehabilitation following this... I feel there are genuinely exceptional circumstances which make this an urgent case.'

This letter was reviewed by the Consultant Orthopaedic surgeon on 24 July 2017. The orthopaedic computer system, BOIS, recorded:
'Letter and email received from GP and patient's [family member] asking for patient to be considered as urgent, seen by [Consultant] and he has said to remain routine.'

No communication was sent to the patient or the GP at the time of the decision to advise of the outcome of the Triage. The patient only became aware of the decision that they should remain on the Routine list on 14 August 2017, following their complaint to the service.

As Patient H and their family remained unhappy they brought their complaint to NIPSO. As part of the investigation Independent Professional Advice (IPA) was requested from a Consultant Orthopaedic Surgeon. Although the IPA confirmed that the decision for Patient H to remain on the routine list was reasonable, they raised concern with the Trust's lack of communication with the GP and the patient:
'... it would have been advisable for [Consultant Orthopaedic surgeon] or a team member to respond to the GP as to the reason why the GP's request to expedite [Patient H's] was being declined. Apart from being in accordance with GMC's standards of record-keeping, this also constitutes professionalism and common courtesy... It is the Trust's responsibility to ensure they are able to reassure patients and GPs adequately when a concern is being raised, more-so as the level of care being provided is far from ideal.'

Impact

This case highlights the distress and frustration resulting from the Trust's lack of communication with patients in regard to the outcome of referrals. It also identifies how this lack of communication demonstrates a failure to adhere to medical professional guidelines.

Case Study 8
Issue: Downgrade in Referral – no communication to patient or referrer

Trust: Western Trust
Medical Specialty: Ophthalmologist

On 29 April 2018, Patient I was referred to ophthalmology as Urgent by their GP. The referral was triaged by a Consultant Ophthalmologist and was downgraded to Routine.

No communication was sent by the Trust to acknowledge the referral or to advise:

- the patient's clinical urgency;
- average waiting time;
- placement on the list;
- what to expect; or
- contact details should more information be required.

On 9 June 2018, under the belief that they had been added to an Urgent waiting list, Patient I contacted the Trust to query how long it would be before they were seen. It was at this stage the Trust informed Patient I they had been graded as Routine and the wait would be up to a year.

Patient I subsequently contacted their GP who sent a further Urgent referral to the Trust, this referral was accepted.

Impact

This case highlights a potential avoidable delay as a result of a patient and GP remaining unaware of the change to the initial referral's 'Clinical Urgency'. This lack of communication removes the ability of the referrer, where necessary, to challenge this decision. In this case, once the patient and GP were made aware of the change, an additional referral resulted in the patient being upgraded and seen within a shorter timeframe.

Personal reflection:

'The organisation down-graded the issues, did not inform myself nor the GP... urgent means urgent.'

Patient I

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Case Study 9
Issue: Referral rejected – patient not informed

Trust: Northern Trust
Medical Specialty: Physiotherapy Neurology Outpatient team

In April 2021 Patient J was admitted to a rehabilitation ward. As part of their discharge plan, on 17 April 2021, the hospital physiotherapist advised Patient J that they would make a referral to the Physiotherapy Neurology outpatient team for further treatment. The hospital physiotherapist recorded within Patient J's medical notes:

'...will refer for OP vestibular rehab..'

Patient J advised they were told

'this would take a few weeks, but shouldn't be too long.'

The Trust's discharge letter to Patient J's GP also confirmed the intent to refer:

'...will be referred as an outpatient for vestibular rehab...'

On 20 April 2021, the hospital physiotherapist sent a referral to the Outpatient Service. However, this was returned, on 25 April with a covering email to the doctor noted on Patient J's discharge summary letter (as opposed to directly returning to the referring physiotherapist). The cover email stated:

'This [Patient] was referred for vestibular rehab. If [their] dizziness is due to volume depletion then vestibular rehabilitation is not appropriate. We are only able to provide vestibular rehab to patients with a neurological diagnosis. As this [patient] does not have such a diagnosis, [they] cannot avail of this service. As a result this referral will be discharged as inappropriate on CRM's unless you wish to discuss this with me further.'

The doctor took no further action. No correspondence was sent to Patient J, their GP, or the original referrer to advise that the referral had not been accepted.

Two months later, having had no communication from the Trust, Patient J, continuing to believe that they had been referred and placed on a physiotherapy waiting list, raised a query with their workplace Occupational Health regarding their wait for physiotherapy, who subsequently identified that Patient J was not on the waiting list.

Impact

This case highlights considerable issues with communication regarding Patient J's waiting list status. The only communication to both Patient J (verbal) and their GP (discharge summary) was confirmation that they would be referred for outpatient physiotherapy.

No correspondence was subsequently sent to Patient J to advise that the referral had been received; that it had been returned to the hospital or that it had been rejected. As a result, Patient J remained uninformed about their waiting list status, incorrectly believing that they had been added to a waiting list and would soon receive treatment.

Had it not been for Patient J being proactive, it is unlikely that the rejected referral would have been detected for some time, and Patient J would have spent even longer under the mistaken belief that they *'just have to wait my turn'.*

Personal reflection:

'...no-one saw fit to communicate this with me, the patient- you know the one who is meant to be at the center of it all - patient centered care and all...How many other patients have slipped through the net due to mistakes like this? Been left sitting thinking am on a waiting list for treatment, when they are not!...'

Patient J

The Trust's failure to communicate Triage outcomes to patients is of considerable concern. Particularly as 85% of respondents to the General Practitioner survey considered that GPs/patients should be informed of changes to their referral, alongside 84% of the General Public respondents considering that '*Clinical Urgency*' should be included within initial waiting list communications. This, alongside the case study examples, is a clear indication that the outcome of referral triage is information patients want, and often need to know.

Chapter Four 'Triage Outcome' Findings

Getting it Right & Being Open and Accountable

Maladministration – Trusts' failure to communicate the outcome of referrals to patients.

The first Principle of Good Administration requires public bodies to '*Get it Right*' by taking account of established quality standards and good practice. The third Principle of Good Administration requires that public bodies should be transparent, open and truthful when accounting for their decisions, stating their criteria for decision making and giving reasons for their decisions.

The communication of Triage outcomes is not only good practice but is required by medical guidance. The Department's response to the investigation also suggests that the IEAP retains the requirement of Trusts to communicate the outcome of referrals.

As the case studies illustrate, neither the patients, nor their GPs, were informed of the triage decision, or the reasoning to downgrade referrals. This failure in communication can potentially result in a missed opportunity to clarify the initial Clinical Urgency and contribute to unnecessary delay in a patient's care and treatment.

Furthermore, as individuals can often rely on the initial '*Clinical Urgency*' verbally communicated by the referrer, the failure to communicate any change raises the potential of significant distress, anxiety and frustration to the patient. Particularly if they become aware at a later date that their referral has been downgraded, often resulting in significantly longer waiting times than they had anticipated.

As current Trust policy makes no explicit reference to the outcomes of referral triage being communicated to patients or referrers (with the exception of red flag referrals and rejections), it raises the possibility that the issues identified within the case studies could be repeated.

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Being Customer Focused

Maladministration – Department's failure to provide clear patient information in relation to triage of referrals and the communication of triage outcomes.

The second Principle of Good Administration states that public bodies should provide clear, understandable policies and procedures, allowing service users to be clear about what they can and cannot expect from the public body.

The above case studies, and the results of the NIPSO survey, suggest that the general public have limited knowledge of the Trusts' Triage process, with 54% of respondents unaware that the Trust could change the '*Clinical Urgency*' recommended by the referrer. The lack of communication with patients about this process has undoubtedly contributed to the low levels of public awareness and the resulting distress to patients on discovering their referral has been downgraded, as illustrated within the provided case studies.

Recommendation 4

The Department and the Trusts should:

4.1 Revise the IEAP to clarify the Triage process and the expectation that patients will be informed of outcomes. As recommended within **Recommendation 3** the outcome should be included within the Acknowledgement to the patient.

4.2 Consider providing additional information on the Triage of Referrals, and what to expect, within the recommended 'Waiting list information' section of the Trust websites (refer to **Recommendation 8**).

Chapter Five

Fundamental Impact on Services

> "There is an obligation & a duty of care by the health department to engage, be transparent & to provide up to date data, that keeps patients informed."
>
> ***Patient***

> "We should also get details if a consultant leaves the Trust and what happens to patients on their waiting list rather than find out by accident that these patients are sitting in limbo with no plans to allocate to another consultant."
>
> ***GP***

> "There is a total lack of transparency for patients on the amount of time they will have to wait for services - some of these services are not even clinically active and effectively a patient is waiting on a list with little or no hope of being seen."
>
> ***GP***

> "The Brackenburn Clinic 'Waiting List' is not in fact any such thing- all those on it are 'waiting' for a service which does not exist; it is not moving at all, has not done so for over 2 years..."
>
> ***Patient family member***

> "Patients have no idea that for example urology is 6 YEARS. They should know that essentially there is no service (6 years is ridiculous) and then can decide about private if they can afford."
>
> ***GP***

> "I have raised a complaint with the Belfast Trust regarding Brackenburn Gender Identity Clinic waiting list not moving in fourteen months. They were unable to provide me with anything but platitudes...I feel utterly voiceless in this..."
>
> ***Patient***

> "Honesty from the Trusts about the waiting lists is required when speaking to patients..."
>
> ***GP***

> "I have been waiting to have my tonsils removed for the last 6 years and still nothing. Every time I rang was told staff shortages."
>
> ***Patient***

> "... [Patient] made it clear that they are not looking to complain about the delays, it is the miscommunication which has them worried."
>
> ***MLA***

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Chapter Five: Fundamental Impact on Services

This chapter focuses on the communications provided to patients when there is a fundamental change or impact to a service.

It has previously been identified[43] that the Integrated Elective Access Protocol (IEAP) lacks sufficient clarity and detail in regard to expected communication with patients.

One of the areas lacking in direction is when, and how, to communicate with patients when a fundamental impact or change to a service has been identified.

Our review of cases identified a number of examples where significant changes or issues had arisen within a service, which fundamentally impacted on patients. For example, where staff shortages were impeding the ability of the service to successfully function for a prolonged period, or where a service was suspended due to safety or ethical concerns.

We considered whether, in these cases, patients were appropriately informed:

Case Study 10
Issue: Fundamental impact or change to service not communicated (Suspension of service to waiting list patients)

Trust: Belfast Trust
Medical Specialty: Gender Identity Services – Brackenburn Clinic

Patient K was initially referred to Brackenburn Gender Identity Clinic (the Clinic) by their GP on 2 March 2017.

In January 2018, the Clinic drafted an internal summary report identifying concerns with the service. The report highlighted resource and surgery provision issues, as well as a fundamental concern with how the service operates. One of the proposed *'next steps'* was to *'close the waiting list and plan for service restructure.'*

In February 2018, the then Deputy Medical Director of the Trust, emailed the Department of Health to propose changes, including the closure of the service to new referrals.

Within this same email the Deputy Medical Director stated:

'3. Obviously this will require significant communication particularly with the service user group. They will understand that we are aiming for improvement, which is what they want, but they will also feel that they are being rejected / not looked after well….'

These proposed changes to the service were not shared with Patient K or any of those held on the waiting list.

On 29 March 2018 Patient K emailed the Clinic to raise concern that they had only moved 2 places since February 2018 and queried why they were moving so slowly. Patient K stated:

43 Refer to Chapters 2, 3 and 4

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'...When I attended the information session with yourselves in December 2017 I was advised about timescales and although I appreciate the service is congested, waiting nearly 2 months to move two places is not what I was advised and is not acceptable...'

In response the Clinic advised:

'...We cannot put a timescale on when a person is seen for a new assessment. When we discharge a patient that is when we can invite a new patient for an assessment...'

No reference was made to the service being '*effectively closed*' to new patients, including Patient K.

Patient K also raised their complaint with Belfast Trust (the Trust). In the Trust's response, dated 28 April 2018, focus was again placed on increased demand being the cause of the waiting time increase.

Within this same timeframe, the Trust wrote to the Health and Social Care Board (HSCB now SPPG) to raise concerns with the Clinic, identifying their decision to temporarily close the waiting list to new patients:

'Further to my previous communication regarding the pressures within Gender dysphoria Services...At present there is not anyone available currently who is appropriately trained as a Consultant to provide modern Gender Dysphoria and Psychosexual services...The Trust is proposing that no further new patients from the waiting list will be commenced on a care pathway from this point on...'

The following year, on 20 February 2019, unaware of this decision, Patient K emailed the Clinic and the Trust's complaint department querying their waiting list status:

'Where am I in the queue?.... I was advised by yourselves that I was number 36 on the list. It has be**en **nearly 12 months since then, and your website states a waiting time of 18 months for a first appointment. I have now been waiting for over 24....'

The Clinic responded (23 February 2019):

'... as previously stated, the BHSCT certainly are taking the issue seriously and doing our utmost, along with the Health and Social Care Board, to negotiate with the Department of Health for the provision of a high quality, responsive and appropriate service. This is not just an issue of resources or funding, but rather the need for a more appropriate service model. Discussions are ongoing...'

The Trust complaints department responded (12 March 2019):

'... the service has continued to experience increased demand, in addition to difficulty with staffing levels to meet such need. A combination of these factors has resulted in growing waiting times for new patients referred to the service... I am deeply sorry that, I am unable to provide you with an approximate timescale for assessment with the Gender Identity Service, at this point...'

Again, neither the Trust, nor the Clinic, advised that an official decision had been taken in March 2018 to not commence any new patients held on the waiting list into the service.

Impact

It is evident that considerable issues have arisen, and are ongoing, within the Gender Identity Service. It is acknowledged that these concerns were raised internally between the Clinic, the Trust, HSCB and the Department, and that steps are being taken to address the issues.

However, it is considerably concerning that a decision to place a hold on new patients entering the service from the waiting list, which ran from 1 April 2018 to 26 September 2020, was never communicated to either Patient K, who had raised concerns, or to all individuals being impacted – the waiting list patients.

I found this lack of communication particularly alarming as the Trust had recognised the need for patient communication at an early stage. However, the only waiting time communications the patients would have received were letters advising of '13 week waits'; '1 year wait'; or the websites advisement at the time of '18 months wait', none of which were accurate given that movement from the waiting list into the service was placed on hold, and no provisional date for the lift of the suspension had been decided.

Case Study 11
Issue: Fundamental impact or change to service not communicated (Service Review)

Trust: Belfast Trust
Medical Specialty: Gender Identity Services – Brackenburn Clinic

Patient L was referred to Brackenburn Gender Identity Clinic (the Clinic) by their GP on 1 March 2017. On 28 July 2019, having been waiting for a first appointment for over two years, Patient L's family member complained to the Trust, requesting an explanation why they had failed to move position on the waiting list.

Within internal Trust emails discussing the complaint, the Service Manager identified that a HSCB review – which had been approved by the Department in March 2019 – was due to take place. However, they indicated that the information should **not** be included within the response to Patients L'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.'

The Trust's subsequent response to Patient L's family member, dated 20 September 2019, did not specifically advise of the planned review, instead it focused on the increase in demand:

'...Similar to other gender clinics across the UK and indeed other health departments in Northern Ireland, there is a rising demand for services of the Brackenburn clinic, thus waiting times are greater that [sic] we would wish for. The Trust is working with the Department of Health and the Health and Social Care Board (HSCB) to look at ways of addressing waiting times and resources at the Gender Identity Service...With regards to waiting times, the Trust had been providing a best estimate time approximation for first appointments. Due to continued rise in demand for the service, at this juncture, we are now advising individuals that we are unable to provide an approximate waiting time so as not to mislead or raise expectations. We are hopeful however that the work underway between the Trust and HSCB will result positively on waiting times...'

Just a few months later, minutes of the Review Group (consisting of both Trust and HSCB colleagues) meetings identified an acceptance that patients should be informed:

September 2019: the group identified that a draft letter to patients had already been prepared and should be cc'd to referring GPs. It was agreed that '*this was fair to keep the lines of communication open with patients' maintaining transparency*'.

November 2019: minutes record that the letters had been amended and issued.

However, a subsequent retraction was noted within the **January 2020** minutes:

'Waiting List Letter [Director] advised that the letter had not been issued to patients on the waiting list – the reason being that other issues had come into play. [Note taker] agreed to amend the notes to reflect this change of position.'

The Trust subsequently confirmed to NIPSO in September 2022 that no formal communication of the review was ever provided to patients.

Impact

This case highlights several concerns in relation to the Trust's communication with those on the waiting list.

In respect of Patient L and their family, the Trust failed to be open and transparent about the review, despite being aware of its commencement at the time queries had been raised.

On a wider scale, it is disappointing to note that this is a further example of the Trust/Gender Identity Service failing to communicate a fundamental impact/potential change to the service, a year on from their initial failure to advise of the suspension of service to new patients. I found this particularly concerning as the Trust itself had recognised the need to inform patients within review group meetings and within correspondence to NIPSO.

In response to our concerns the Trust advised:

The Trust, instead of contacting patients on the waiting list, shared information with service users who were currently in treatment, both face to face at keyworker appointments, and via email on occasions. Information was

also displayed on the Brackenburn Clinic website, and individuals who contacted the clinic querying their place on the waiting list were informed of the regional review and listening events.'

It further advised that information was published on the website on 11 November 2019, 16 days before the Review Group's first listening event. This was subsequently removed after just 11 weeks, on 29 January 2020. As the draft report for this review was not completed until March 2022 it is unclear why this information was removed, and why it was not simply updated.

Case Study 12
Issue: Fundamental impact not communicated as standard

Trust: Southern Trust
Medical Specialty: Orthopaedic Surgery

On 12 December 2019, Patient N attended an orthopaedic surgery consultation. At this consultation the patient states they were informed their clinical urgency was being upgraded from the Routine waiting list to Urgent, and that their surgery would take place within the next two months. A clinic letter, typed on 23 December 2019, carried the instruction:

'Follow Up: Proceed to surgery list as an urgent case.'

The same month Patient N was advised they would be added to the Urgent waiting list, orthopaedic surgeries were cancelled due to a workforce issue with respect to theatre nurses. The Trust states that this decision was taken a week before Patient N's appointment.

Patients held within the elective surgery list, including Patient N, were not informed of this suspension/cancellation of services.

Orthopaedic elective surgery did not begin again for 3 months. At this point medical staff reviewed the patients on their waiting lists to ensure the correct pathway for each patient was being followed. It was during this review that an error occurred which caused Patient N to make a complaint.

It was only for this reason that Patient N was subsequently advised of the suspension of the surgeries, and the purpose of the subsequent review of clinical information.

Impact

In this case a suspension/cancellation was applied to the elective orthopaedic surgery list. Although this impacted on those placed within the waiting list (and impacted on their wait time expectations) this information was not provided as standard to all those affected.

Personal reflection:

'How have the actions of the organisation affected you?

'Distress and Anger, Ignored, very annoyed, humiliated.'Patient N

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I am concerned by the lack of communication in these cases and by the level of persistence required, by the few individuals who felt equipped to raise their concerns, before clear information was provided. I will consider this requirement for persistence in **Chapter Eight: Access to information**.

Despite these concerning cases, I acknowledge and welcome that this investigation also identified instances where good communication was put in place:

Case Study 13
Good Practice: Communication around suspension of services

Trust: Belfast Trust
Medical Specialty: Gender Identity Services – Brackenburn Clinic

In 2017, Patient O was in the process of being referred for gender reassignment surgery at a hospital within Great Britain (GB). Referrals are made to GB as the surgery is unavailable in Northern Ireland.

Following the identification of a significant concern, and the hospital's own internal investigation, a decision was taken by the Trust on 7 April 2017 to temporarily suspend patient attendance and treatment at the GB hospital.

On 13 April 2017, the Gender Identity Clinic (GIC) wrote to Patient O, and others potentially impacted, to advise of the suspension:

'Unfortunately, we must advise you that for as yet indeterminate length of time the Belfast Health and Social Care Trust is going to have to suspend your attendance and treatment at this Service... We hope this will only be for a short period. The reason for this is that there has been a significant concern raised about governance procedures in [GB hospital]... We will of course keep you up to date with any changes to this situation.'

Six months later, on 24 October 2017, the Trust sent an update letter to Patient O. This letter was also sent, on the same date, to all those identified as being potentially impacted by the suspension:

'... I would like to update you as to the current position. Unfortunately we have still not received the required assurances from [GB] that would allow us to resume work with them...Negotiations and investigations are continuing but as yet we have not reached a satisfactory and acceptable resolution. We have also made enquiries of alternative providers but have been informed that there are excessive waiting lists. As a result, they are not in a position to accept new referrals. I am sorry that this is the current situation and do appreciate that it is extremely frustrating and difficult for you. However, we continue to work towards finding an acceptable resolution. You will be updated as soon as further information is available. In the interim, if you need any support, please do not hesitate to get in touch with your Therapist or the Brackenburn Clinic Service.'

On 20 April 2018, the Trust agreed that governance concerns had been addressed and the suspension could be lifted, 12 days later, on 2 May 2018, the Trust sent a letter to update those impacted – including Patient O:

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'Further to my correspondence of 14th April 2017 and 24 October 2017, I am pleased to inform you that the Belfast Health and Social Care Trust is now in a position to resume referrals for gender reassignment surgery to [GB hospital]. The Belfast Health and Social Care Trust has recently received the required assurances of the provision of safe and effective care. I apologise for the lengthy delay incurred by this process. However, please be assured that our focus is always on the provision of high quality and safe care for the population whom we serve. Please do not hesitate to contact me or your keyworker if you require further clarification.'

Impact

This case identifies good practice in communication. The Trust undertook reasonable steps to inform those impacted about both the decision to suspend referrals and the decision to lift the suspension. It was also open within its update to patients that negotiations remained and that, although alternatives had been considered, these were unfortunately not viable.

It is also noted that the Trust provided an additional form of support by encouraging individuals to get in contact with the clinic, with the provision of a direct line number.

[It should be noted that the review of this case is focused solely on the Trusts approach to communication – how patients were advised, kept updated and informed about how their waiting list status would be affected. Our review did not consider the hospital investigation; the reason for concern; or the Trust's actions to reinstate referrals or consider alternatives.]

It is of note that the Gender Identity Service in Brackenburn Clinic is highlighted in this chapter as an example of both poor communication and good practice. Whilst good practice is always to be welcomed it will be frustrating for the GIC patients and their families who experienced poor communication, to see the clinic being highlighted as an example of effective communication. This in my view, further illustrates the uncertain landscape for patients in relation to waiting list communications, as even within one medical specialty the quality and nature of communication was found to vary significantly.

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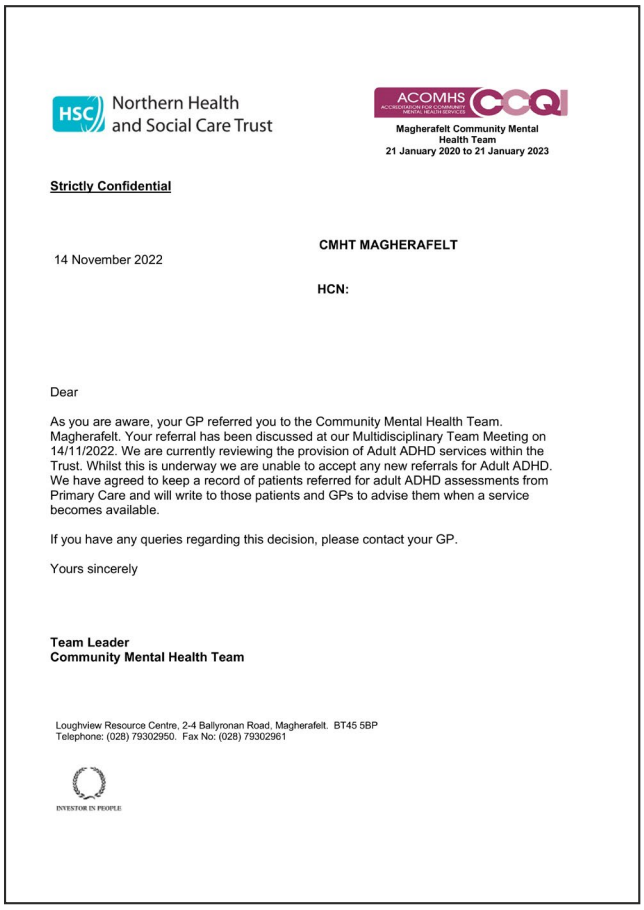
Good Practice Example 2 – Adult Attention Deficit Hyperactivity Disorder

Whilst not a case study like the previous example, during the investigation it was identified that a regional review of Adult Attention Deficit Hyperactivity Disorder (ADHD) services had resulted in the new referrals to the service no longer being accepted within the Northern Trust.

It should be noted that the service issue, and the review itself, has not been considered within this investigation as this sits outside of the terms of reference. However, we queried with the Northern Trust how this issue, which was a fundamental change to the service, was communicated to the patients affected.

In response, the Northern Trust provided assurance that all patients, referred prior to this decision[44], were honoured and offered an appointment. Those referred after the decision, were provided with the following correspondence:



HSC Northern Health and Social Care Trust

ACOMHS CCQI
Magherafelt Community Mental Health Team
21 January 2020 to 21 January 2023

Strictly Confidential

14 November 2022

CMHT MAGHERAFELT

HCN:

Dear

As you are aware, your GP referred you to the Community Mental Health Team. Magherafelt. Your referral has been discussed at our Multidisciplinary Team Meeting on 14/11/2022. We are currently reviewing the provision of Adult ADHD services within the Trust. Whilst this is underway we are unable to accept any new referrals for Adult ADHD. We have agreed to keep a record of patients referred for adult ADHD assessments from Primary Care and will write to those patients and GPs to advise them when a service becomes available.

If you have any queries regarding this decision, please contact your GP.

Yours sincerely

Team Leader
Community Mental Health Team

Loughview Resource Centre, 2-4 Ballyronan Road, Magherafelt. BT45 5BP
Telephone: (028) 79302950. Fax No: (028) 79302961

INVESTOR IN PEOPLE

It is welcomed that the Northern Trust informed patients of the service provision issue at the outset and offered assurance that an update will be provided. I am however concerned to note that patients have been referred to their GP for further information. It is likely that the service would be better equipped to provide advice on the decision.

44 November 2021

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Chapter Five 'Fundamental Impact' Findings

Being Customer Focused & Be Open and Accountable

Maladministration – Department's failure to provide guidance to Trusts; and the Trusts' failure to provide communication, as standard, when a fundamental impact on a service is identified.

The second Principle of Good Administration states that public bodies should provide clear, understandable policies and procedures, allowing service users to be clear about what they can and cannot expect from the public body. The third Principle of Good Administration requires that public bodies should be transparent, open and truthful when accounting for their decisions, stating their criteria for decision making and giving reasons for their decisions.

The IEAP does not currently contain guidance on what communication should take place when a fundamental impact on a service is identified. Patients and Trusts are therefore unaware of what to do or what to expect.

The case studies identify that although Trusts had made significant decisions in relation to service provision – which impacted on patients - they were not open and honest with the patients affected. A failure to communicate this information can result in significant distress, anxiety and frustration. It is also, a missed opportunity to engage with patients and request their participation when a review of a service is undertaken.

Recommendation 5

5.1 When a Trust/medical specialty become aware of a fundamental issue with a service, which is likely to have a significant impact on waiting times, they should inform all affected patients identifying:

- the issue;
- any steps being taken to remedy the issue;
- the likely impact on waiting times – if known;
- what to expect; and
- details on who to contact should more information be required.

5.2 The Department should revise the IEAP to reflect these changes.

Chapter Six

Removal from the Waiting List

"A short time ago, and with no other communication since the update when the pandemic hit, I got a letter from the Trust to say 'my surgery was deemed to be no longer needed', no reason for this decision, just basically go away. A complete and utter disgrace."

Patient

"Patients are frequently discharged because patient hasn't contacted them [Trust] after letter sent requesting them to phone to make an appointment. But often patients haven't received this.Common cause for re-referral in my experience."

GP

"I was mistakenly removed from the waiting list without notification."

Patient

"I received a letter from the booking centre in April 2022 asking if I still required to see someone, they still had no appointments for me as of yet and if I didn't respond within 2 weeks I would be taken off the waiting list."

Patient

"The only communication from the Trust was a letter, after several years on the waiting list, asking me to confirm if I still wanted an appointment."

Patient

"Only communication I received was to ask if I still wished to continue on the waiting list. A validation exercise but no information."

Patient

"Communication only asked me to indicate if I still required my appointment. No further information or advice."

Patient

"I was seeing an ENT consultant every 6 months or so before covid. To my HORROR and disbelief he discharged my case in March 2020 without notice or consultation. It was only after investigation by myself that I discovered this and now I am at the bottom of the waiting list again!"

Patient

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Chapter Six: Removal from the Waiting List

This chapter focuses on the communication process the Trusts undertake to inform patients they may be, or have been, removed from a waiting list.

Patients may, at times, be discharged (removed) from a waiting list. There are a number of potential reasons for removal, for example[45]:

- a patient may not attend a booked appointment;
- they may cancel an appointment on multiple occasions;
- they may not respond to an invitation to book an appointment;
- they may inform the Trust they no longer require an appointment/procedure;
- a clinician may review the patient, or their records, and decide they no longer require assessment or treatment.

The IEAP sets out guidance for Trusts regarding removal from waiting lists, including the expected communication to patients, and the process for potential reinstatement:

Sample extracts from IEAP:

2008 IEAP appendix: ***Implementation procedure for patients who cancel or do not attend***

'Where patients are removed from the waiting list following a DNA, a letter will be sent to the patient and the General Practitioner explaining that the patient has been removed from the outpatient waiting list.'

'Following discharge patients will be added to the waiting list at the written request of the referring GP and within a four week period from date of discharge. Patients should be added to the waiting list at the date the written request is received.'

Same wording in the main body of April 2008 IEAP in relation to:

4.9 PATIENT CANCELLATIONS (CNAS) AND DID NOT ATTENDS (DNAS)
[The same extract is repeated in further sections]

Main body of June 2020 IEAP:

'2.7.1. DNAs – New Outpatient
If a patient DNAs their new outpatient appointment the following process must be followed:

'2.7.1(a) *Patients who have been partially booked will not be offered a second appointment and should be removed from the waiting list. The patient and referring clinician (and the patient's GP, where they are not the referring clinician) will be informed that, as they have failed to attend their appointment, they have been discharged from the waiting list…'*

'2.7.1(d) *Where patients are discharged from the waiting list (ref. 2.7.1(a)) they should be advised to contact the Trust booking office within four weeks of*

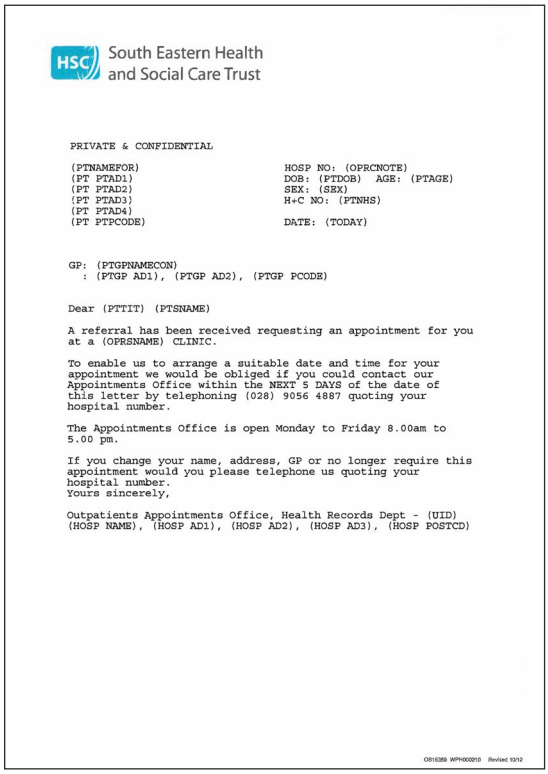
45 These examples have been provided by way of a general illustration; they are not an exhaustive list of potential scenarios where a patient may be removed

the original appointment date if they consider that the appointment is still required. Where a patient makes contact within the four week deadline, and where the Trust considers that unforeseen or exceptional circumstances meant that the patient was unable to attend, the patient should be added to the waiting list at the date that they have made contact with the Trust. If a patient makes contact after the four week period they cannot be reinstated.'

As part of this investigation, we considered stages where patients may be removed from the list; what the IEAP states should happen in these cases; and how the Trusts applied the policy. The review focused on 3 stages: non-response to appointment letters; non-attendance to an appointment; and validation exercises.

Non-response

Once a patient comes within a 6 week timeframe of a potential appointment the Trusts, in many cases, send patients a '*partial booking letter*'. This letter requests that the patient contacts the Trust to agree a suitable appointment date and time. Samples of these letters are provided below:



South Eastern Health and Social Care Trust

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(PTNAMEFOR)
(PT PTAD1)
(PT PTAD2)
(PT PTAD3)
(PT PTAD4)
(PT PTPCODE)

HOSP NO: (OPRCNOTE)
DOB: (PTDOB) AGE: (PTAGE)
SEX: (SEX)
H+C NO: (PTNHS)

DATE: (TODAY)

GP: (PTGPNAMECON)
: (PTGP AD1), (PTGP AD2), (PTGP PCODE)

Dear (PTTIT) (PTSNAME)

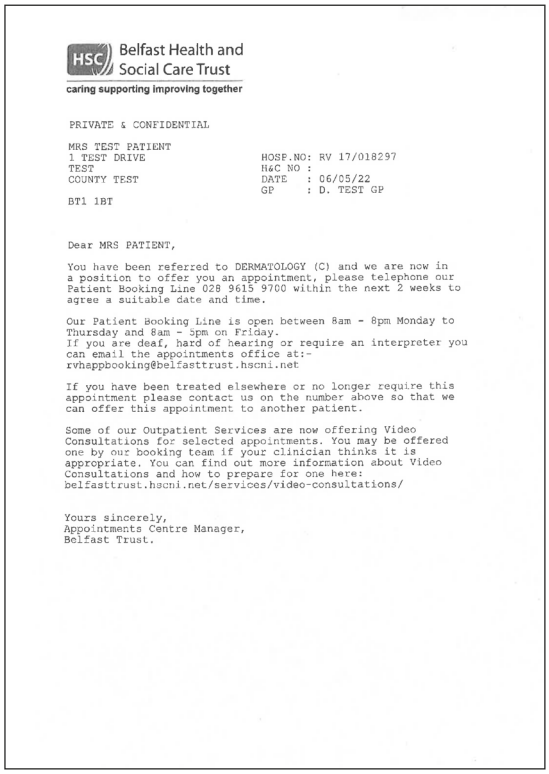
A referral has been received requesting an appointment for you at a (OPRSNAME) CLINIC.

To enable us to arrange a suitable date and time for your appointment we would be obliged if you could contact our Appointments Office within the NEXT 5 DAYS of the date of this letter by telephoning (028) 9056 4887 quoting your hospital number.

The Appointments Office is open Monday to Friday 8.00am to 5.00 pm.

If you change your name, address, GP or no longer require this appointment would you please telephone us quoting your hospital number.
Yours sincerely,

Outpatients Appointments Office, Health Records Dept - (UID)
(HOSP NAME), (HOSP AD1), (HOSP AD2), (HOSP AD3), (HOSP POSTCD)



Belfast Health and Social Care Trust
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MRS TEST PATIENT
1 TEST DRIVE
TEST
COUNTY TEST

BT1 1BT

HOSP.NO: RV 17/018297
H&C NO :
DATE : 06/05/22
GP : D. TEST GP

Dear MRS PATIENT,

You have been referred to DERMATOLOGY (C) and we are now in a position to offer you an appointment, please telephone our Patient Booking Line 028 9615 9700 within the next 2 weeks to agree a suitable date and time.

Our Patient Booking Line is open between 8am - 8pm Monday to Thursday and 8am - 5pm on Friday.
If you are deaf, hard of hearing or require an interpreter you can email the appointments office at:-
rvhappbooking@belfasttrust.hscni.net

If you have been treated elsewhere or no longer require this appointment please contact us on the number above so that we can offer this appointment to another patient.

Some of our Outpatient Services are now offering Video Consultations for selected appointments. You may be offered one by our booking team if your clinician thinks it is appropriate. You can find out more information about Video Consultations and how to prepare for one here:
belfasttrust.hscni.net/services/video-consultations/

Yours sincerely,
Appointments Centre Manager,
Belfast Trust.

Although the IEAP sets out clear guidance on the action that must be taken by the Trust, should a patient not attend or cancel a partially booked[46] appointment, it does not include reference to the expected communication, or discharge process, to be applied to patients who have not responded to '*book*' an appointment.

Following review of Trust partial booking letters, it became apparent that, in the absence of standard guidance, there are a number of areas in which the Trusts approach to removal, and communications, vary.

46 Following the patient contacting the Trust and agreeing an appointment time and date, the patient is considered to be 'partially booked'

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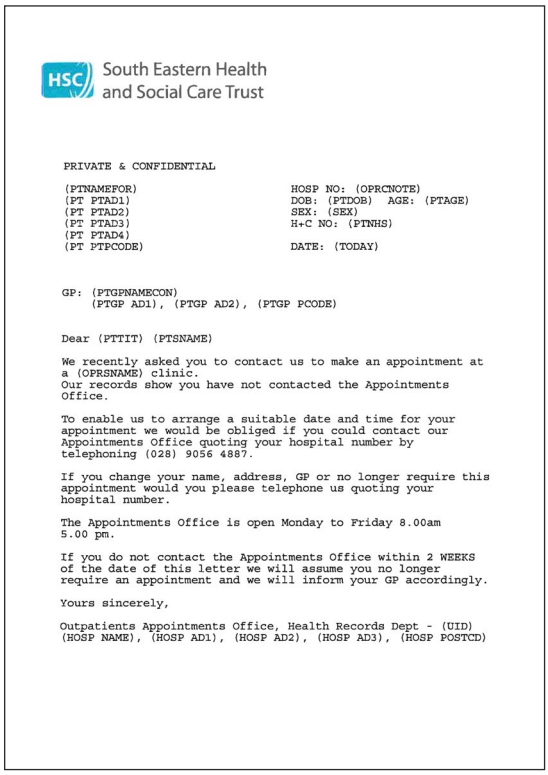
a. Timeframes to contact before removal

Once a partial booking letter is sent, patients are expected to contact the Trust within a certain timeframe to agree an appointment. If a patient fails to contact the Trust following the initial letter, a reminder letter will be sent advising that, if the patient does not contact the Trust, they will be removed from the waiting list.

The examples illustrated within this chapter (both letter templates and case study), identify that Trusts vary in the length of time they provide patients to make contact. Some Trusts allow a total of 3 weeks, while others provide 10 working days (refer to **case study 14**).

Those Trusts which provide a total of around 3 weeks to respond, also vary in how this timeframe is split between the initial letter and the reminder letter. For example, the previous templates illustrate how South Eastern Trust's booking office initially provide 5 days to respond to a partial booking letter, while Belfast Trust provides 14 days. This timeframe is subsequently swapped within the reminder letter:



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(PTNAMEFOR)
(PT PTAD1)
(PT PTAD2)
(PT PTAD3)
(PT PTAD4)
(PT PTPCODE)

HOSP NO: (OPRCNOTE)
DOB: (PTDOB) AGE: (PTAGE)
SEX: (SEX)
H+C NO: (PTNHS)

DATE: (TODAY)

GP: (PTGPNAMECON)
(PTGP AD1), (PTGP AD2), (PTGP PCODE)

Dear (PTTIT) (PTSNAME)

We recently asked you to contact us to make an appointment at a (OPRSNAME) clinic.
Our records show you have not contacted the Appointments Office.

To enable us to arrange a suitable date and time for your appointment we would be obliged if you could contact our Appointments Office quoting your hospital number by telephoning (028) 9056 4887.

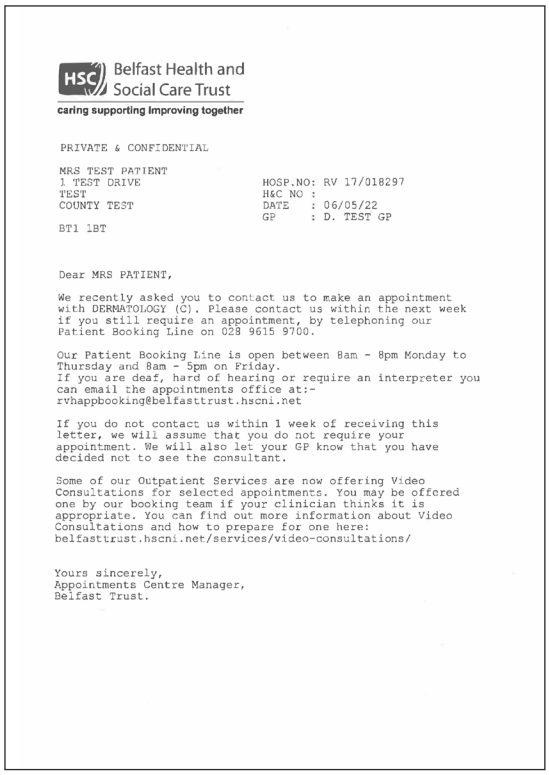
If you change your name, address, GP or no longer require this appointment would you please telephone us quoting your hospital number.

The Appointments Office is open Monday to Friday 8.00am 5.00 pm.

If you do not contact the Appointments Office within 2 WEEKS of the date of this letter we will assume you no longer require an appointment and we will inform your GP accordingly.

Yours sincerely,

Outpatients Appointments Office, Health Records Dept - (UID)
(HOSP NAME), (HOSP AD1), (HOSP AD2), (HOSP AD3), (HOSP POSTCD)



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MRS TEST PATIENT
1 TEST DRIVE
TEST
COUNTY TEST

BT1 1BT

HOSP.NO: RV 17/018297
H&C NO :
DATE : 06/05/22
GP : D. TEST GP

Dear MRS PATIENT,

We recently asked you to contact us to make an appointment with DERMATOLOGY (C). Please contact us within the next week if you still require an appointment, by telephoning our Patient Booking Line on 028 9615 9700.

Our Patient Booking Line is open between 8am - 8pm Monday to Thursday and 8am - 5pm on Friday.
If you are deaf, hard of hearing or require an interpreter you can email the appointments office at:-
rvhappbooking@belfasttrust.hscni.net

If you do not contact us within 1 week of receiving this letter, we will assume that you do not require your appointment. We will also let your GP know that you have decided not to see the consultant.

Some of our Outpatient Services are now offering Video Consultations for selected appointments. You may be offered one by our booking team if your clinician thinks it is appropriate. You can find out more information about Video Consultations and how to prepare for one here:
belfasttrust.hscni.net/services/video-consultations/

Yours sincerely,
Appointments Centre Manager,
Belfast Trust.

These different timeframes may not only lead to confusion for patients who are being treated within multiple Trusts/medical specialties but may also lead to a level of unfairness.

For example:

- Those who are referred to a Trust who impose a total response timeframe of 10 days are in a less favourable position than those who are referred to a Trust who impose a 3 week timeframe.
- As only the reminder letter advises of potential removal, those who are provided with a shorter period (5 days or 1 week) to contact once this letter is received, are in a less favourable position than those who are provided with 2 weeks.

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b. Notification of reinstatement policy – partial booking removal

As identified within the IEAP, where a patient is removed from a waiting list there are, at times, opportunities to be reinstated. Reinstatement is the process where a patient may be placed back on the waiting list without the requirement of a new referral from the General Practitioner (GP).

However, the IEAP does not provide clear guidance on whether the reinstatement policy should apply to those who are removed following non-response to partial booking letters.

The removal notification templates provided by the Trusts, identify variation in provision of reinstatement advice to patients who do not respond. For example, Belfast Trust advises patients that they may contact the Trust within 4 weeks of their removal to request reinstatement, whereas Northern Trust simply refers the patient to their GP. Northern Trust's template letter to the GP also makes no reference to reinstatement. Instead, the letter asks the GP to re-refer the patient if the appointment is still needed.

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MRS TEST PATIENT
1 TEST DRIVE
TEST
COUNTY TEST

BT1 1BT

HOSP.NO: RV 17/018297
H&C NO :
DATE : 06/05/22
GP : D. TEST GP

Dear MRS PATIENT,

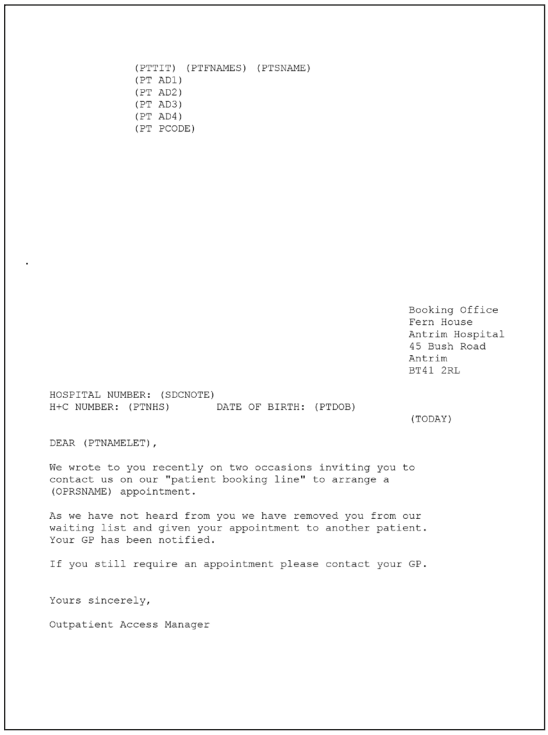
We wrote to you recently on TWO OCCASIONS inviting you to contact us on our "Patient Booking Line" to arrange an appointment with DR C MCCOURT, DERMATOLOGY (C).

As we have not heard from you, your name will now be removed from the outpatient waiting list and your GP will be informed that you no longer wish to see DR C MCCOURT.

If you still require an appointment please contact the Patient Booking Line at the number below within the next 4 weeks.

If you are deaf, hard of hearing or require an interpreter you can e-mail the appointments office at: rvhappbooking@belfasttrust.hscni.net

Appointments Centre Manager,
Belfast Trust.
Tel: 028 9615 9700



(PTTIT) (PTFNAMES) (PTSNAME)
(PT AD1)
(PT AD2)
(PT AD3)
(PT AD4)
(PT PCODE)

Booking Office
Fern House
Antrim Hospital
45 Bush Road
Antrim
BT41 2RL

HOSPITAL NUMBER: (SDCNOTE)
H+C NUMBER: (PTNHS) DATE OF BIRTH: (PTDOB)

(TODAY)

DEAR (PTNAMELET),

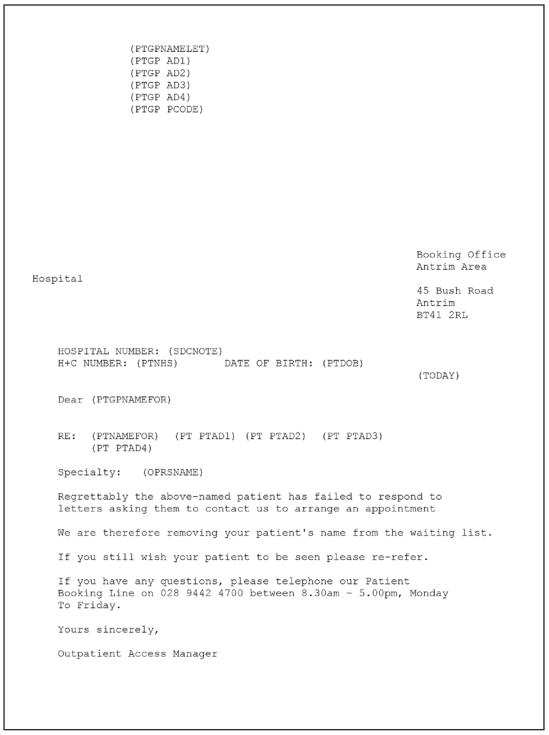
We wrote to you recently on two occasions inviting you to contact us on our "patient booking line" to arrange a (OPRSNAME) appointment.

As we have not heard from you we have removed you from our waiting list and given your appointment to another patient. Your GP has been notified.

If you still require an appointment please contact your GP.

Yours sincerely,

Outpatient Access Manager



(PTGPNAMELET)
(PTGP AD1)
(PTGP AD2)
(PTGP AD3)
(PTGP AD4)
(PTGP PCODE)

Booking Office
Antrim Area

45 Bush Road
Antrim
BT41 2RL

Hospital

HOSPITAL NUMBER: (SDCNOTE)
H+C NUMBER: (PTNHS) DATE OF BIRTH: (PTDOB)

(TODAY)

Dear (PTGPNAMEFOR)

RE: (PTNAMEFOR) (PT PTAD1) (PT PTAD2) (PT PTAD3)
(PT PTAD4)

Specialty: (OPRSNAME)

Regrettably the above-named patient has failed to respond to letters asking them to contact us to arrange an appointment

We are therefore removing your patient's name from the waiting list.

If you still wish your patient to be seen please re-refer.

If you have any questions, please telephone our Patient Booking Line on 028 9442 4700 between 8.30am – 5.00pm, Monday To Friday.

Yours sincerely,

Outpatient Access Manager

The gaps in the IEAP guidance in regard to non-response to partial booking letters has likely facilitated the variation in approach by the Trusts, the impact of which is illustrated within the following case study:

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Case Study 14
Issue: Removal and reinstatement

Trust: Northern Trust
Medical Specialty: Orthopaedics

Patient P was first added to a waiting list for the MSK (musculoskeletal) Pain Service following a GP referral on 10 December 2017.

They subsequently received a partial booking letter from the Trust on **9 February 2018**, inviting them to make an appointment by phoning the Appointments Department within **5 working days** of the date of the letter.

The letter made no reference to the potential removal from the waiting list if Patient P failed to respond.

According to the Trust, following non response, a further reminder letter was sent on **16 February 2018** offering another **5 working days** to respond. Patient P disputes that they received this reminder.

Patient P subsequently received a letter dated **24 February 2018** informing them that, as they had not responded to the invitation to book an appointment, they had been discharged.

Patient P was provided with a total of 10 working days, or 15 days, from the date of the first partial booking letter, before they were discharged.

On 2 March 2018 Patient P complained to the Trust, copying their letter to their MLA, and the Patient and Client Council, stating:

'You wrote to me on 9 Feb advising that I had 5 days to contact the Department for an appointment...you wrote again on 24 February to advise that I had been discharged. I called on 1 March to explain I had been suffering from the flu and your operator told me there was no possibility of my discharge being reconsidered. Fifteen days is a very short time to allow someone to respond to a summons, given that at least one day will expire in postage. Many people take two weeks holiday during which they might be written to and discharged without any possibility of responding. Levels of flu are higher than average this year and two weeks is not an unusual time for someone to be incapacitated. Older people and the ill may not be in a position to respond as quickly as others, not to mention people with dementia. I accept that in this case you have followed your own protocol but the protocol is absurd. Whoever thought it up did not think it through...'

In response to Patient P's complaint, on 24 March 2018 the Trust provided Patient P with a response detailing the steps it had taken, including a chronology of letters that it states were sent. They further stated:

'Patients can be reinstated in exceptional circumstances, and I apologise this option was not offered to you.'

Patient P was subsequently reinstated to the waiting list, however they remained concerned with the Trust's response and subsequently complained to NIPSO:

'While I am happy to be offered reinstatement it continues to be the case that a person can be discharged from the service just because of a reasonable absence on holiday or, as in my case, a brief unavoidable illness. It is by no means clear that I would have been offered reinstatement without the intervention of my MLA and many people would be unable to mount an effective complaint, perhaps due to sheer illness or other vulnerability.'

Impact

This case identifies the issues which can arise from a lack of clear guidance, and the resultant variation in approach.

It is accepted that when Patient P first contacted the Trust, the telephone operator did not offer any suggestion of potential reinstatement. The lack of any guidance within the IEAP, as to what should happen in the case of non-response to partial booking letters, means that this is not unexpected.

However, this issue becomes confused by the Trust's subsequent response to Patient P's complaint which suggested that there was a reinstatement policy, and that the telephone operator failed in their responsibility to offer this.

In order to clarify this issue, this investigation queried the application of the policy with the Trust:

During a site visit by NIPSO to the Trust on 24 May 2022, it was discussed that patients have a period of 4 weeks post-discharge to request reinstatement to the waiting list.

a. Can the Trust confirm that the 4 weeks reinstatement policy is applicable to all discharges, i.e. DNA's; non-response to partial booking; etc?

I can confirm that this applies to all, however this was not our policy in 2017 or 2018. This was an amendment to IEAP in reinstating after 4 weeks which came into effect in December 2021.

b. Can the Trust advise why there is variation in the provision of this information in written communications i.e. this information is not included within the discharge letters sent to individuals who do not respond to partial booking letters but it is included within DNA discharge letters.

The amendment in 2021 to reinstate within 14 days applied to CNAs and DNAs not the partial booking process. Patients are given 2 opportunities to respond to the partial booking service a total of 10 days.'

As shown, the Trust's responses provided further uncertainty. While in response to the first question the Trust confirms that the 4 weeks reinstatement policy applies to non-response to partial booking letters, within its subsequent response the Trust advises that it does not.

The Trust also goes on to advise that the policy was not in place in 2017/2018. It is accurate that the 2008 IEAP (which was the version of the guidance available in 2017/2018) suggested that only a GP could request a reinstatement within four weeks, and this changed in the June 2020 version to include patient requests. However, this raises further queries as to why the Trust suggested the telephony operator should have offered reinstatement to Patient P in 2018. Not only had Patient P been discharged due to non-response to their partial booking letter, which is not explicitly included within the IEAP reinstatement policy, but it was also Patient P, not their GP, who was requesting reinstatement.

In response to the draft investigation report it is noted that the Trust accepted that this response was made in error. It provided clarification that the four week reinstatement required by the IEAP is applicable only to discharges following DNA. It is therefore unclear why it was applied in response to Patient P's complaint.

It is welcomed that in this case the Northern Trust eventually provided Patient P with the opportunity to be reinstated. However, the lack of clear, well

publicised guidance leads to confusion on behalf of both patients and Trust staff, raising the potential that patients may be treated differently, dependent on which Trust they are referred to.

It is also welcomed that during the investigation the Northern Trust advised it had noted inconsistencies within communications, which it aims to address.

Personal reflection:

'It is by no means clear that I would have been offered reinstatement without the intervention of my MLA and many people would be unable to mount an effective complaint... Although my personal situation has been addressed, the public interest has not. I would like the Ombudsman to ask or require the Trust to address the problem which clearly exists in its service provision and to provide appropriate assurances about future performance.'

Patient P

Did Not Attend (DNA[47])

Notification of reinstatement policy – DNAs

In contrast to partial booking, the IEAP does provide advice that a four week reinstatement policy should apply to a patient who is removed from the waiting list following non-attendance to a booked appointment. As previously described, a change to the 2008 policy also meant that, since December 2021, patients, rather than GPs, can request reinstatement themselves.

However, review of DNA removal notification templates, and Trust responses, identified that this reinstatement policy is not always included within communications to patients:

'The Trust confirms this message is not included within discharge/ removal letters following DNA.'

Southern Trust

'Following a DNA it is noted on the discharge letter that the patient can contact the booking office within 4 weeks from date of letter if they still require an appointment'

Northern Trust

'If a patient rings within 4 weeks of being discharged following DNA they can be reinstated. We currently don't communicate this to patients in the form of a letter.'

South Eastern Trust

'GPs are notified when a patient Does Not Attend (DNA) by the Consultant's Secretary. There is no standard template as this is a dictated letter by the Clinician'

Western Trust

'A patient may be reinstated if responding within 4 weeks of notification of removal. A sample letter is included at Appendix 6'

Belfast Trust

47 DNA – A DNA is defined as a patient who is offered a reasonable date for an outpatient appointment and fails to turn up on the day without giving any notice

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This issue was also raised by GPs within interviews conducted as part of this investigation:

'...across all Trusts they have this four weeks in place where if somebody rings within four weeks of being discharged then they will be reinstated, but there's variation in whether that information is placed within the letter or not. So some letters will advise people they can, some won't, it will just advise them they've been discharged. But in the main we're getting there with it but there still needs to be a lot done...It's not rocket science. I can't for the life of me get a good explanation as to why they should vary in the way that they do, other than each little silo has its own nuance. It frustrates me immensely... You know, just change it, just make the thing the same so that everybody's getting the same information every time and I get a copy of it.'

GP

'We don't always get letters that say they can be reappointed, that's just simply not correct, it's not a one hundred per cent thing... Some services are very good about it, flagging it, and patients do rebook; other people just send a different DNA letter... The thing about PAS is, [not great] and all as it is at some things, it's quite good at others. You have a stock of template letters. So it has never been clear to me why [some] DNA letters are just basically one-liners from Word that say, "We've tried to contact your patient, we haven't been able to, we've discharged," and yet there is a perfectly good PAS patient-centred template that gives all of this information, that you can just change the specialty name and, to say, "If there's a reason that you didn't attend an appointment, and you do want it, just ring this number to rebook."...'

GP

This inconsistency in communication may, again, raise a level of unfairness to patients, as depending on the Trust in which they are referred, they may remain unaware of the ability to request reinstatement.

Validation

In order to '*validate*' waiting lists the Trusts may undertake exercises to review patients to determine whether they still require an appointment/procedure. This procedure was first identified within the 2006 IEAP:

Extract taken from 2006 IEAP:

'Patient validation is essential to establish that all patients registered for their first appointment still require to be seen. This should take place on a rolling basis at the intervals outlined below. No patient should receive patient validation correspondence if they will be partially booked within the next 8 weeks (see letters in appendices).

- *13 weeks*
- *32 weeks*
- *52 weeks..'*

There are typically 2 methods used by the Trusts:

- **Clinical Validation** – this involves a clinical team/health professional review of the patient – typically through review of their case notes. Following review,

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the health professional makes a determination as to whether or not the patient still requires an appointment or procedure.

- **Administrative Validation** – this involves a letter or text message being sent to the patient to enquire whether they still require the appointment – for example a patient may have had treatment privately, or they may no longer feel it necessary to have an appointment. Like partial booking letters, if a patient does not reply to a validation text/letter within a certain timeframe, they will be removed from the waiting list. The exception to this is where an inpatient/Daycase patient does not respond. In this case a health professional is expected to review the patient's notes before making a decision.

The following is a template letter held within the 2006 IEAP which is still in use by some Trusts/Specialties.

Outpatients Appointments Validation Office

Hospital Number:

Dear

You were referred to us on DATE for a SPECIALTY outpatient appointment. We want to reassure you that you have not been overlooked, and regret it has not been possible to give you a date for your appointment.

Sometimes patients change address, have had their appointment at another hospital, or decided they no longer want the appointment and forget to let the hospital know. To ensure we still have your correct details it would be appreciated if you would check the enclosed form and return it to us in the pre-paid envelope provided.

If you require any further information please contact us on our direct telephone line _____

Yours sincerely

Outpatient Appointments Manager

Hospital Number:

Speciality:

Consultant:

Patients Name

1st line address
2nd line address
3rd line address
Post code

PLEASE AMEND ANY OF THE DETAILS ABOVE IF THEY ARE INCORRECT

What is your phone number?

Home Number: _____

Work Number: _____

Mobile Number: _____

Please tick the appropriate Boxes:

I Still Want To Have An Appointment ☐

I Have Had An Appointment Elsewhere ☐

I No Longer Want To Have An Appointment ☐

OTHER COMMENTS: _____

SIGN: _____

DATE: _____

DRAFT

Although validation of waiting lists was first introduced within the 2006 IEAP, this investigation identified that this process has not been regularly undertaken. However, in recent years, the focus has been renewed.

HSCB (now SPPG) provided a direction to the Trusts in June 2019 that all patients waiting longer than 52 weeks, as of 31 May 2019, should be validated. The Waiting List Management Unit (WLMU) is also now responsible for the oversight of these exercises.

The comments provided within the General Public Survey (**see the cover pages to this Chapter**) would suggest that validation is becoming more commonplace, with many of the respondents suggesting that the validation letter or text message was the only waiting list communication they have received.

Nevertheless, concerns were raised about the content of these communications. For example, the General Public Survey identified that a significant number of respondents felt that very little information was provided to them to explain the reasons behind the decision to remove them.

It would also appear that when a clinical validation exercise is being undertaken, the Trusts do not communicate this action to patients – unless a decision is subsequently taken to remove them. This is potentially a missed opportunity for the patient to highlight a change in their health which may be relevant but not contained within their notes.

These concerns were reiterated by the GPs who engaged with our investigation through the survey and/or interview:

'we recently got a bunch of standard letters taking people off screening [Specialty] due to new guidance – did not tell us what guidance was. Also it was signed Southern Trust validation team No clinician name; No email or phone number. I tried to contact back as I disagreed with the decision on one patient, but no-one could tell me in CAH [Craigavon Area Hospital] how to contact the "validation team". I had no option but re-refer to bottom of waiting list.'

GP

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'In 2021 oral surgery wrote to GPs to say "do they still need seen?", GPs [were] to write back within 6 weeks or they [patients] are off waiting list - no information to patient. This meant I had to review the patient before re-referral. No letter from oral surgery since!!'

GP

'So for patients who are already known to secondary care but are just waiting for, say, a review, the letters we tend to get are "We've reviewed this patient's clinical records and we don't feel that they require further follow-up and they've been discharged" even though they were seen a year earlier and it's said, "Review in five months" or four months or something, which I find kind of difficult because I'm thinking, "Gosh, if somebody felt they needed seeing again and now they've been discharged and the patient has that expectation that they were being seen again, that's tough," and it tends to be that they still have the problem and you end up having to re-refer them. There is another letter sometimes that I've seen coming out, usually for new referrals to say, "We've been reviewing and…" something maybe along the lines of that "We don't feel this patient needs to be seen, could you forward us more information within so many weeks or this patient will be discharged." That's tough because sometimes you haven't seen the patient again, you know, so things probably haven't changed, and you've already made the clinical decision that you feel that they do need to be seen and they're saying they don't, so where do you stand?…'

GP

'The letter that says, "We contacted the patient to see if they still require this Appointment and they don't." That's okay. What I worry is someone looks at somebody's notes and thought, "Well I don't need to review, I'll just take them off." I have issues with that, I think a patient has to be involved if they're going to be taken off a waiting list.'

GP

It is of considerable concern that the Trusts would undertake such a significant decision without first engaging with the patients held on the list to make them aware that a clinical validation process is underway. It is further concerning that, where a decision is subsequently made to remove a patient, the Trusts are not providing the patient, or the GP, with an appropriate level of reasoning for this decision.

Receipt of letters

The investigation's analysis of General Public and GP Survey comments, identified further concerns that the communications the Trust send to patients, may not always be received.

As non-response to letters can result in a patient's removal from the waiting list, this suggestion of non-receipt is of particular concern. The investigation therefore considered potential causes:

a. Non-receipt - at same address

A number of respondents to the General Public survey - who had been removed from a waiting list - commented that they had been unaware of their removal until

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they had contacted the Trusts (**examples of quotes provided within cover page**).

Their removal may have been for a variety of reasons. However, as any decision to remove a patient from a waiting list typically has a requirement to inform the individual, this theme of non-notification, raises concerns that a letter has either not been sent, or it has not been received.

Whilst it is possible that non-receipt of a letter is a result of a change in address (which will be considered later in this chapter), worryingly the investigation identified instances where patients had reported non-receipt despite remaining at the same address. For example, as previously discussed, in **Case Study 14**, Patient P advised they had not received a reminder letter to contact the Trust.

Further detail is provided in the following case study:

Case Study 15
Issue: Non-receipt of letters

Trust: Northern Trust
Medical Specialty: Orthopaedics

As previously highlighted, Patient P disputed they had received a copy of the reminder letter from the Trust in **February 2018**. This is of particular significance as it is the reminder letter, not the initial partial booking letter, that advises of the Trust's policy to remove following non-response.

The Trust were asked as part of this investigation to provide a copy of this reminder letter, alongside the discharge letter sent to the GP.

Within its response the Trust provided scanned copies of letters which all contained the date the letter was printed for the purposes of the investigation - **13 November 2022**. The Trust advised that the date displayed was a result of the date resetting to the date of printing. It further advised that the PAS system contains patient letter history which indicates a second letter was sent on 16 February 2018.

Impact

It cannot be confirmed that the Trust did not send the reminder letter, it also cannot be confirmed that the letter was sent and received by Patient P.

This raises concern of potential issues with the provision of letters to patients. It also queries any reasoning the Trusts might have as to why they do not advise patients of the removal policy within both the initial letter and the reminder letter.

This same issue of non-receipt was highlighted by a GP during interview:

'I've only seen the discharge letters... "They didn't make contact" or "We couldn't get them." That's all I see. Now, those sort of letters, I... Again, this generates a wee bit of work and I tend to personally just take a wee glance, especially if it's something urgent or especially if it's somebody I know and I'm like, "God, no, they don't miss appointments, this isn't like them," I will double-check that the address is the same. And maybe even sometimes I phone the patient myself and say, "Look,

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do you realise you've been discharged here?" And, to be honest, you usually tend to find they don't or they tend to say they never got a letter. From a personal experience, I'll not go into detail but I needed ...to get physiotherapy routinely..., I did get a letter in the post but the date clashed so I phoned up to rearrange it and was told, "No problem, we'll get you a new date." No new date ever came. But [subsequently] they were able to tell me in the hospital, "Oh you didn't attend your physio follow-up" and there it was in ECR, there was a letter, one of the discharge letters to say, "Patient did not attend and discharged." And I actually had been waiting for the letter to come through. So now when patients tell me, "I never actually even got a letter," you know, I actually do believe them. And it's not to say that the Trust or anything is lacking but it's happened to myself, and I hadn't moved address ... And some of the patients... I have to physically go away and search it up, and I'll say, "Actually you've been discharged." And patients are like, "Well I never got a letter." And you know some of these poor patients are struggling, and would be waiting on that letter, and they wouldn't miss it at all.'

GP

b. Non-receipt - Change in address

An obvious reason for a letter not being received is that a patient may have changed address. As many patients have remained on waiting lists for a considerable time, this raises the likelihood that contact details may have changed.

'Very likely to have moved address when waiting years to be seen. Need to have option to easily change address of referral without having to submit a new referral. Patients often try to update address details with secondary care and then often inform me still not received anything. Especially difficult with asylum seekers living in hotels, who will often have moved by time hospital contact.'

GP

'[People] are particularly bad and I hold my own hands up in this as well, we have moved address and I haven't thought to ... it's obviously a stressful time in people's lives and I haven't thought to update the GP and any hospital clinic that needed to be informed. The problem is we would tend to find that it's people in lower socioeconomic groups that are moving address more frequently. They're the ones that are obviously going to be most negatively [affected] by this. For a large part if you're living in rented accommodation, for example, personally I think there will be more moves there and there will be more potential for those people to fall out of the system.'

GP

This investigation therefore considered how patients are made aware of the importance of notifying changes in address, and what checks are undertaken by the Trusts prior to a letter being sent.

How do patients know to change their details?

It is acknowledged that some Trust correspondence templates contain a statement which encourages a patient to inform the Trust of changes to address.

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However, as identified within **Chapter Three: Acknowledgements**, in the past, Acknowledgements were infrequently sent. Although some medical specialties have reinstated this practice, others have not. This opportunity to alert patients of the need to advise of changes is therefore often lost.

This investigation has also identified that, in the majority of cases, no further waiting list communications are sent to patients, other than a potential validation letter or a partial booking letter (which are not sent in every case). Again, this is a lost opportunity to regularly remind patients of the need to advise of contact detail changes.

How are addresses verified by the Trusts?

The IEAP does not set out a standard process for address verification. As part of the investigation the Trusts were therefore asked what procedures they undertake to verify addresses ahead of sending out correspondence.

The Trust responses identified that, whilst the majority suggest they undertake some form of verification at the point a referral is received, there is wide variation in the approach to additional checks being taken prior to a partial booking or validation letter. This included whether:

- A check of Northern Ireland Electronic Care Record (NIECR) is undertaken, (NIECR is a database which allows for any changes to addresses, including through the GPs, to be viewable to the Trusts);[48]
- An internal policy is in place which details address checks;
- The GP is contacted to verify details, and whether this contact is made after non-response to the 1st letter or 2nd letter; and/or
- The patient is contacted to verify details.[49].

In many cases a significant period of time may lapse before a patient receives an appointment or validation letter. It is therefore concerning that some Trusts may undertake limited, if any checks, prior to sending this letter out. Comments submitted by GPs reinforce this concern:

'ECR has patient demographics and in my experience the Trusts do not confirm addresses using it. I can also safely say they would never phone a patient to confirm address despite numbers usually available on referral and on ECR.'

GP

'Frequently appointment letters [are] sent to wrong addresses despite new addresses having been updated on GP system/ECR. Personally, have had appointment letters repeatedly sent to previous address despite it having been updated with GP, correct on ECR and advised when I attended the hospital initial review.'

GP

'Multiple occasions where Trusts have incorrect address for patient (despite correct address being on referral letter) and have discharged them. Despite this being the Trust's error, it inevitably results in the GP having to do a new referral'.

GP

48 This step was the most commonly suggested verification step by the Trusts
49 This step was the least suggested step by the Trusts

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'Sometimes that can happen. There sometimes needs to be a little bit of detective work even phoning the patients. Look, some departments are more guilty than others in having instances where the patient is never seen to receive a letter even though the Trust has indicated that they have made all efforts to contact that individual. I'd like to have a little bit more detail or an audit on what 'all efforts' were and not just two letters. Where people are marginalised and homeless, they are particularly challenging to track down. And those people that have mental health problems and in many cases I'm trying to get them appointments, I'm trying to get them letters to the right place – it's really, really hard so we need to find other ways to communicate with these people; it can't just be about a letter.'

GP

The variation in Trust approach to verification of addresses, and the lack of any clear standardised policy, is again likely to have contributed to the experiences described by the GPs and patients. It has also potentially contributed to the Trusts' ongoing concern with the level of patients who fail to attend appointments, and the significant reduction[50] in waiting lists following Administrative Validation exercises.

Although fixed appointment letters[51] were not specifically considered within this chapter, if errors in verification of address are occurring, either through administration or a lack of awareness of patients to inform the Trust of changes, then it is likely that some missed attendances are a result of patients not receiving the letter. It is also likely that non-response to validation letters is occurring for the same reason. Patients may be slipping through the net, or are only becoming aware of the issue if a GP contacts them following receipt of a discharge letter.

To assess the validity of this potential issue, some of the Trusts were asked to provide reinstatement figures linked to a fixed appointment that had not been confirmed by the patient. The WLMU was also asked if it held the reason for reinstatements following validation removal. In response both advised that they do not hold this information.

Chapter Six 'Removal from the Waiting List' Findings

Being Customer Focused, Being Open & Accountable and Acting Fairly and Proportionately

Maladministration – lack of guidance and clarity in how Trusts communicate with patients about removal from, and reinstatement onto, waiting lists.

The second Principle of Good Administration requires public bodies to inform customers what they can expect and what the public body expects of them. The third Principle of Good Administration requires public bodies to be open and clear

50 Evidence provided to the investigation suggests that the reduction can at times be as high as 25-30%
51 Unlike partial booking letters, fixed appointment letters are sent to a patient with a fixed date and time for attendance

about policies and procedures, and ensure that information and any advice provided is clear, accurate and complete. The fourth principle of Good Administration requires public bodies to deal with people and issues objectively and consistently.

There are a number of communication related issues about how people are removed from and / or reinstated to a waiting list that are not meeting these standards. The ramifications of which could result in patients missing treatment or having to re-join the bottom of a potentially lengthy waiting list.

Firstly, the lack of guidance within the IEAP in relation to partial booking removal process has led to variation in approach across Trusts. As has the lack of clarity in the provision and communication of the reinstatement policy. As a result, some patients may be provided with longer periods of time to respond to the Trust and avoid removal / get reinstated than others. Also, some patients may be alerted to the ability to request reinstatement, while others are not.

Furthermore, the lack of communication regarding clinical validation exercises, often leaves patients feeling that they have been '*left in the dark*'. Opportunities to remind patients of the importance of keeping their contact details updated are missed due to the general lack of communication.

The collective impact of these communication issues for patients is potentially confusing and unfair, with the quality and clarity of communications dependent on individual Trust practice rather than a consistent NI wide standard of service.

Recommendation 6

The Department and the Trusts should:

6.1 Revise the IEAP to provide clear guidance to the Trusts on the processes to be applied to non-response to partial booking letters.

6.2 Introduce standard partial booking templates to be used across all Trusts (and all specialties) providing the same timeframe for response. Both the initial letter and the reminder letter should include potential removal advice.

6.3 Ensure that all discharge letters refer to the 4 week reinstatement policy. Trusts should also make it clear whether a reinstatement to the waiting list will mean the patient will be placed back to the same position on the list, or at the end of the list.

6.4 Review the current clinical validation letters and consider the comments provided by the patients and the GPs in response to this concern. The letter should be amended to ensure appropriate information/detail is provided on the reasons why patients are being discharged/removed from the waiting list.

6.5 Introduce a verification of address policy to be applied across all Trusts as standard. In respect of non-response, the policy should include consideration of additional checks of NIECR and GPs prior to removal of the patient. Staff should be retrained accordingly.

6.6 Undertake engagement with patient representative bodies to identify ways in which notification of changes in addresses may be improved.

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Chapter Seven

Clinic Letters

> "Think of the independent Neurology inquiry, think of Michael Watt's patients... had the letters been addressed to the patient and copied to the GP, because people would've gone, "Hold on a minute, that's not the diagnosis I was told in clinic" or "Hold on, I don't see reality reflected in this letter." So I don't think that you need to go alone saying, "The Northern Ireland Public Services Ombudsman's office feel that this practice [of letters to GPs without patient CC'd] is wrong." "
>
> ***GP***

> "I think to copy a patient into a letter would be brilliant just from a patient understanding point of view, from taking a wee bit of pressure then off the GP but even off secondary care that they're not re-phoning secretaries to say, "Am I on a list for surgery or not?"
>
> ***GP***

> "Ideally the communication should go to the patient with the GP copied into this. This will empower the patient/carer/ advocate to be responsible for being able to actively follow it up in an informed way."
>
> ***GP***

> "Have had no communication since my appointment with a consultant, impossible to speak to consultant or secretary, just get answer machine, never call you back."
>
> ***Patient***

> "I think it's brilliant when the letter goes to the patient and I think the patients appreciate it too, the majority of patients. So I can think of one consultant in our local area – although I don't know if they're there anymore – who was sending letters to the patients and they were brilliant...It was just in good layman's terms and we were just copied into it and we could understand too... So we don't need massive amounts of detail, if they want to give us more detail that can be put on to a separate letter, but it was enough for the patient to understand it... what I think happens is a lot of the time a patient leaves clinic ...they can't remember what they've said or they've forgotten to ask something or they don't know what the plan is or maybe the plan just hasn't been made very clear, so then they're coming into us... "
>
> ***GP***

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Chapter Seven: Clinic Letters

This chapter focuses on the letters dictated by health professionals following a clinic attendance, and who these letters are provided to. It will also highlight the role clinic letters should play in helping people manage and make decisions about their health needs.

Following an appointment or consultation with a patient, the health professional will dictate a letter which typically summarises:

- the patient's background and condition;
- what was discussed; and
- the next steps in terms of treatment, or management of their condition.

Often, these letters will also contain information relevant to patient referrals and waiting list status. For example, a health professional may confirm within the letter that the patient has been added to a waiting list for treatment/procedure/diagnostic testing.

It is therefore unsurprising that, across the UK, it is common practice for these letters to be provided directly to patients; a practice which is encouraged within a range of medical guidance and publications:

'Best practice for most outpatient letters is writing directly to patients… The PRSB standard for outpatient letters is designed to improve and standardise the content of outpatient letters so that professionals, patients and carers receive consistent, reliable, high quality information between clinicians and patients' [52]

Professional Record Standards Body

'The clinic letter provides several vital functions:

- *It forms part of the patient's permanent clinical record*
- *It communicates management plans to the GP*
- *It supports the communication of clinical information and treatment plans to the patient*
- *It provides patients with their own record, which serves as a reminder of what has been discussed, as well as providing the opportunity to alert the clinician of any inaccuracies or changes made by other clinicians.*

… all patients should be sent a letter (whether written directly to them or sent as a copy), unless they explicitly decline.' [53]

Royal College of Psychiatrists

52 Outpatient Letter Standard, Professional Record Standards Body, Outpatient letter v2.1 – PRSB (theprsb.org)
53 Royal College of Psychiatrists, '*Writing clinic letters: College guidance on improving engagement with patients*', January 2021

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'Writing letters directly to patients is in keeping with Good Medical Practice, which states: 'You must give the patients the information they want or need to know in a way they can understand' and the NHS Constitution, which states that patients '... have the right to be given information about the test and treatment options available to [them], what they involve and their risks and benefits' and have 'the right of access to [their] own health records and to have any factual inaccuracies corrected'. The NHS Constitution also states that staff should 'involve patients, their families, carers or representatives fully in decisions about prevention, diagnosis, and their individual care and treatment'.

'... The benefits of writing directly to the patient rather than sending them a copy of a letter written to their GP have long been recognised... Doctors who have adopted the practice say their communication style has become more patient-centred. GPs find the letters easier to understand and spend less time interpreting the contents for the patient. Most importantly, patients find such letters more informative, supportive and useful...' [54]

Academy of Medical Royal Colleges

I was therefore concerned to note that, the majority of Northern Ireland's Trusts, do not send a copy of the clinic letter to the patient, unless it is expressly indicated by the health professional. This means that, typically, the letter is only sent to other health professionals, for example, the patient's GP.

In providing the investigation with reasoning for this approach, the Trusts placed an emphasis on verbal communication – referring both to the health professional's ability to provide information to the patient during the appointment, and to the GP, who the Trusts advise, can update the patient once they receive the clinic letter (refer to **Chapter One: The Role of the General Practitioner** for further detail).

It is agreed that health professionals should communicate and advise patients of relevant information during the appointment. However, it is unrealistic to assume that patients will always be able to understand and retain the verbal information. This is particularly the case for appointments taking place at a stressful or difficult time or for patients receiving unexpected or complex information.

It also suggests an expectation that, on all occasions, health professionals consistently update a patient accurately and comprehensively.

The Trusts' decision to not, at the very least, provide patients with a copy of clinic letters (which are already typed and available as part of health professional practice) is a missed opportunity to confirm/clarify the information verbally provided to them. It is also a missed opportunity to provide reassurance to patients that any follow up action discussed within the consultation, subsequently took place.

54 Academy of Medical Royal Colleges, *Please, write to me - Writing outpatient clinic letters to patient: Guidance*, September 2018

In order to illustrate these missed opportunities, I have included a number of case examples:

Case Study 16
Issue: Clinic letter not shared with patient

Trust: South Eastern Trust & Belfast Trust
Medical Specialty: Gynaecology

Patient G has a background of learning difficulties, as well as a number of significant medical conditions which require ongoing treatment and management. It is therefore important that both the patient/family members and their GP are kept updated with the latest clinical information.

The following are a small number of examples and extracts of the information held within clinic letters:

Date of clinic: 7 July 2018
Date letter sent: 5 August 2018
Letter sent to patient: No

'...[They are] on prophylactic antibiotics for these but understandably [their parent] is concerned given the fact that [Patient G] has had multiple episodes of bacterial meningitis following neurosurgery... We will review [Patient G] in one months time with these blood results and if normal the plan would be to stop [their antibiotics]. We have also placed [Patient G] on the list for a [device] change at this stage...;

Date of clinic: 5 August 2018
Date letter sent: 7 September 2018
Letter sent to patient: No

'...I reviewed [Patient] today. All of [their] investigations have been normal : [they have] no autoimmune deficiencies and [they are] not diabetic. Nasal swabs etc were negative. I think really [they] could stop antibiotics now. I understand you have successfully changed the [device] and that is fantastic. I have not arranged a further review but of course would be very happy to see [them] should it be necessary...'

Impact

This case identifies the considerable information provided within clinic letters which is not being shared directly to the patient. The examples provided identify planned reviews; addition to a waiting list for a procedure; further treatments and follow ups – including a recommendation that antibiotics should have stopped – a concern that had been expressed by the patient's family member.

The provision of written confirmation, in addition to verbal communication at the time of the appointment, would keep the patient/representative informed and provide assurances (or highlight concerns) in regard to the agreed care.

I am also concerned by the time which has elapsed between the date of the clinic and the date the letter was typed/sent. This is of particular concern as the letters contain recommendations in relation to medication.

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Case Study 17
Issue: Clinic letter not shared with patient

Trust: Belfast Trust
Medical Specialty: Ear Nose Throat Department/Surgery/ Endocrinology

Patient Q was diagnosed with thyroid cancer on 3 July 2016. On 9 July 2016, the consultant referred the patient to Endocrinology for consideration of radioactive iodine treatment, and dictated a clinic letter to Patient Q's GP.

Date of clinic: 3 July 2016
Date letter sent: 9 July 2016
Letter sent to patient: No

'...at 42 mms [they] would require radioactive iodine treatment and I have therefore arranged for completion thyroidectomy to be performed. I will arrange to discuss [them] at the multidisciplinary team meeting in the interim and I will be in touch in due course with the outcome from that. Arrangements have been made for [their] readmission on 13/6/16 for theatre the following day.'

Despite this letter advising of proposed treatment, further action, and confirmed dates of the patient's procedure, Patient Q was not provided with a copy of the dictated letter.

Following their surgery, Patient Q states they were advised that they would be referred on for radioactive iodine treatment and would be seen within 6-8 weeks. They also state they were provided with no further information or support regarding what to expect.

Extracts of Discharge letter sent to GP:
Date of admittance: 14 July 2016
Date of Letter: 24 July 2016
Letter sent to patient: No

'...[they] have been referred to Dr [x], Consultant Endocrinologist with a view to radioactive iodine....I will see [them] at the outpatient clinic shortly to discuss the results further and [they] should be hearing from Dr [X] shortly.'

On 21 July 2016, Patient Q states they received an Acknowledgement letter which stated they had been placed on the waiting list for radioactive iodine treatment and that they would be contacted again approximately 6 weeks prior to an outpatient's appointment. Patient Q advised this letter caused great anxiety:

'not only was there no date for even an initial consultation, let alone treatment and the vague "6 weeks" notification represented only the first point of contact rather than the timescale in which I had been led to expect the treatment would be concluded.'

Following persistent contact made by the Patient, they were seen by Endocrinology on 5 September 2016. Radioactive iodine treatment was

subsequently planned for 8 October 2016, 12 weeks after their surgery, not the 6-8 weeks they state they were verbally advised.

Following treatment, Patient Q attended a number of further clinics, including the below:

Date of clinic: 2 March 2018
Date letter sent: 20 March 2018
Letter sent to patient: No

This letter discussed the results of testing and progress. It further stated:

'I would be grateful if you could repeat [their] thyroid function tests in two months time and I have asked [them] to let me know when this has happened so I can review [the] results and modify [their] dose of [medication] if required. I checked thyroglobulin level today and will add the result to this letter and have planned further review in six months.'

This letter not only provides an indication of placement on an outpatient review waiting list, but it also serves as a reminder for further action required from the patient.

Impact

This case highlights several potential issues that may arise from the lack of provision of clinic letters, including, the potential risks of relying solely on verbal communication.

As consultations may take place at a particularly fraught time, it raises the risk that information may not be readily absorbed/taken in by the individual, or may not be fully explained by the health professional. Had Patient Q received a copy of the letters, they may have felt reassured by the action taken. Alternatively, they may have been provided with an earlier opportunity to query timeframes and/or advice.

In addition, some of the examples may have served as a reminder of agreed action, including the patient's own recorded action to update the consultant.

Ultimately this lack of follow up information, is a missed opportunity to keep patients informed and provide additional reassurance about the actions taken.

Personal reflection:

'While stating that the cancer diagnosis had been something that I and my family could cope with, we stressed that the circumstances in which the diagnosis had been delivered and the subsequent lack of support and information had made a bad situation much, much worse.'

Patient Q

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Case Study 18
Issue: Clinic letter not shared with patient

Trust: Belfast Trust
Medical Specialty: Fertility Centre

Patient O attended a consultation to discuss fertility preservation:

Date dictated: 8 July 2018
Date letter sent: 27 July 2018
Letter sent to patient: No

The letter included reference to testing, including hormone levels and scans. It further referenced potential follow up – re-referral:

'... [Patient O] has had blood taken to measure their level of anti-mullerin hormone as well as FSH, LH and Oestradiol levels and I have told them I will write to them regarding the results. I had to explain to them however that there is currently no funding for fertility preservation for transgender patients. This situation may change and if so [Patient O] would be keen to pursue egg harvesting and freezing. We have left it that [They] will contact the Regional Fertility Centre in approximately six months' time to enquire if there has been a change to the funding arrangements and if so I would be very grateful if you could refer [them] back again.'

Impact

This case identifies the considerable information provided within Clinic letters, which is not then shared directly to the patient.

The example provided, highlights the communication of a significant funding decision and agreed follow up actions, including confirmation of the requirement of the patient to follow up with further enquiries and potential re-referral.

Although there are clear indications that information has been shared verbally with the patient, a written follow up would reassure the patient of the action being taken and provide an opportunity for the patient to review and consider this again, within their own time. This would potentially allow for patients to have a better understanding of their consultations and planned treatment.

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Case Study 19
Issue: Clinic letter not shared with the patient

Trust: South Eastern Trust & Belfast Trust
Medical Specialty: Gynaecology

Patient R was on a waiting list for a period of approximately 4 years, during which they attended a number of clinics and appointments.

While there are examples in this case of some letters being copied to Patient R this did not happen with every attendance. Listed below are some examples:

Date of clinic: 27 July 2017
Date letter sent: 27 July 2017
Letter sent to patient: No

This letter provided a brief overview of the patient's condition and results of a scan. It further stated:

'With regard to surgery, [they] are happy for [their] left ovary to be removed. I have therefore confirmed [their] name to be on our urgent waiting list...'

Date of clinic: 17 September 2018
Date letter sent: 8 October 2018
Letter sent to patient: No

This letter included important waiting list information including:

'I discussed the case with Dr [X] and [they] were happy to board [Patient R] for radical laparoscopic excision of endometriosis +/- oophorectomy + Mirena coil insertion as an urgent case'.

Date of Clinic: 22 July 2019
Date letter sent: 6 August 2019
Letter sent to patient: No

This letter provided significant details and commentary on diagnostic testing and results. It further recorded the planned follow up:

'After discussion today by gynae, radiology and colorectal team, based on the significant endometriosis on MR, the first recommendation is to change the laparoscopic surgery to laparotomy. [Patient R] will be reviewed at [Dr X] clinic to discuss laparotomy as well as proceeding to more definitive surgery with pelvic clearance rather than excision of endometriosis. It is also felt that whilst this patient awaits their surgery they will likely benefit from GnRH analogues and thus these will be started at their next clinic review.'

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Impact

This case identifies the considerable information provided within clinic letters, which is not then shared directly with the patient.

The examples provided highlight confirmation in regard to planned surgery; addition to waiting lists and Clinical Urgency.

Whilst it is not suggested that this information was not provided verbally, it remains the case that written follow up would reassure the patient of the action being taken, and potentially provide a better understanding of consultations and planned treatment.

Chapter Seven 'Clinic Letters' Findings

Being Customer Focused & Being Open and Accountable

Maladministration – Trusts' failure to provide clinic letters directly to patients.

The second Principle of Good Administration states that public bodies should provide services that are easily accessible to their customers. The third Principle of Good Administration states that public bodies should give people information and, if appropriate advice, that is clear, accurate, complete, relevant and timely.

Clinic letters, for some patients are a key component of waiting list communications. Although they do not feature within the IEAP, this quote from the current version of the IEAP sets out very clearly the importance of timely and accurate communication with patients:

'Ensuring prompt timely and accurate communication with patients is a core responsibility of the hospital and the wider local health community.'

IEAP June 2020

I believe this aspiration is one that should hold true for patients regardless of what stage their care and treatment is at.

It is acknowledged and welcomed that Belfast Trust have recognised the importance of providing clinic letters to patients, and have recently implemented internal guidance which states:

'The Trust now expects that all letters to GPs (including ED discharge letters) are copied to patients as a matter of course unless consultant medical staff explicitly state that the letter must not be. It is also acceptable to write to patients and copy to GPs'

Whilst it is noted that this revised guidance places an emphasis on providing patients with a copy of the letter, rather than writing directly to the patient, it

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remains a significant improvement to the approach of the other Trusts.

By failing to provide clinic letters to patients, Trusts are not being open with patients or providing them directly with information which is relevant to their care. This communication failure creates opportunities for patients to feel confused/unsure about timescales and next steps regarding their treatment.

The Trust's dependence on health professionals to provide verbal information to patients (also highlighted within **Chapter One: The Role of the General Practitioner**), and their introduction of discretion as to whether written confirmation of information is provided, may also lead to inequality, as some patients may receive more information than others.

I was also concerned to note that a number of the cases reviewed as part of this investigation, identified a significant lapse in time between the date of the clinic, and the date the letter is typed and sent. I am concerned, given the nature of the information within these letters, that they are not timely. Particularly where recommendations are made in regard to medication and follow up testing.

Recommendation 7

7.1 The Department should publish guidance on clinic letters which will apply across all Trusts and specialties. This guidance should include:

- The expectation that clinic letters will be copied to both the GP and the patient unless the health professional explicitly states otherwise;
- The requirement to record reasons where a letter is not sent;
- Encouragement to health professionals to write the letter directly to patients; and
- Expected timeframes for dictation and sending of letters.

Ahead of publication of this guidance – the Trusts should implement the sharing of clinic letters with patients with immediate effect.

7.2 The Department and the Trusts should undertake a compliance review six months from the date of this report, across all specialties and Trusts, to determine if this practice is consistently applied. Where non-compliance is identified, it is expected that reasons will be recorded, and further action will be taken.

7.3 The Department and the Trusts should also review best practice guidance regarding communicating with patients and consider how this can be implemented, including consideration of resource requirements and potential impact for other services. These considerations should be recorded, and further action noted.

When considering this recommendation, I recall my previous Own Initiative Investigation into Personal Independent Payments (PIP)[55]. The PIP investigation identified that individuals typically hold limited medical evidence relating to their condition/s.

The aim of this recommendation is to keep patients informed about their care and treatment. However, an offset is that it may also lessen the necessity of individuals who require the support of benefits, to seek out medical evidence themselves. This may also reduce the number of claimant requests made to GPs/health professionals for medical information to support their claim.

55 https://nipso.org.uk/site/wp-content/uploads/2021/06/NIPSO-Own-Initiative-Full-report.pdf

Chapter Eight

Access to Information

"I phone the consultant's secretary to find any information and she is extremely helpful and courteous."
Patient

"I was able to communicate with the secretary about queries who was really helpful."
Patient

"... I tried all different phone calls, a lot of different lines, and when I did get through they'd just say, "If you're on a routine waiting list we're not taking your call." So what I discovered was through a friend of mine who worked in the hospital ... he went and enquired about my waiting list."
Patient

"Complaints about the lack of progress and failure to communicate have been filed with NHSC Trust and Belfast Trust - the former missed the 20 day deadline to respond, the latter has still not provided a definitive answer."
Patient

"I haven't had any information,I've had to ring my surgeon's secretary to get told anything."
Patient

"Feel like information is provided if you have time and energy to phone up and chase it but not readily provided."
Patient

"I have not been able to contact the Secretary of my Consultant until today after trying for 3months. Just went to voicemail and no call back after providing my number."
Patient

"I have had no communication since my appointment with a consultant, impossible to speak to consultant or secretary, just get answer machine, never call you back."
Patient

"I have received no information at all since my consultant verbally told me she was referring me for an MRI scan. I have myself contacted the specialist nurse to ask for an update and was told I am still on list."
Patient

"I had to take a complaints procedure against the trust to try and get some answers."
Patient

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Chapter Eight: Access to Information

This chapter focuses on the accessibility of waiting list information.

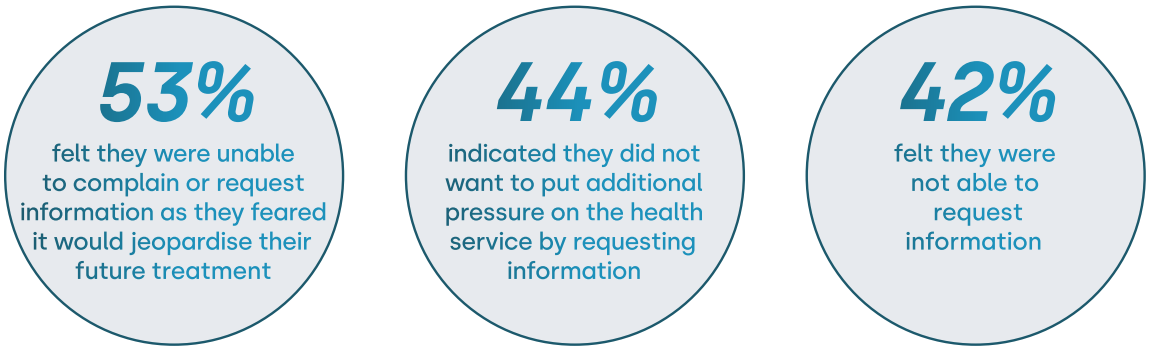
As highlighted within previous chapters, Trusts typically provide limited waiting list information directly to patients. The onus is therefore placed on patients[56], and/or their representatives, to seek information through enquiries and/or complaints.

Our investigation found that, despite patients identifying a clear desire for waiting list information, their ability to access this information is not always straightforward.

Those who are unable to complain

Our General Public survey found that a significant number of respondents were reluctant or felt unable to access information:

Figure 8.1 General public survey respondents reluctant or unable to access information



These barriers potentially place individuals at a significant disadvantage, as the evidence reviewed by this investigation suggests that, often, information and potential redress is only gained by raising enquiries and/or complaints:

Case Study 20
Issue: Complaint resulting in additional waiting list information

Trust: Southern Trust
Medical Specialty: Orthopaedic Surgery

As identified within Case Study 12, Patient N complained to the Trust following a concern with their case notes, which was identified within a waiting list review.

As a result of this complaint Patient N was informed that surgeries had been suspended from December 2019 to March 2020. They were also informed of the purpose of the subsequent review/validation of cases held on the surgical waiting list.

Other patients on the same waiting list were not afforded the same information.

56 70% of survey respondents identified that they only received information on their waiting list status when they requested it

Impact

This case identifies that a patient was provided with significant information, relevant to their waiting list, solely as a result of their complaint. Those patients who did not raise an enquiry or a complaint are unlikely to have been aware of this delay, despite it being relevant to their expected waiting time.

Case Study 21
Issue: Complaint resulting in Upgrade in Clinical Urgency

Trust: Belfast Trust
Medical Specialty: ENT

As identified within Case Study 4, Patient D waited a significant period of time before they were placed on an '*Urgent*' waiting list for surgery.

Patient D complained to the Trust in November 2020 stating:

'I wish to make a complaint in relation to the length of time it has taken for me to receive the surgery I require. I understand with the current COVID 19 pandemic things have been put on hold but my case has been going on long before COVID19...'

In its response, dated 16 January 2021, the Trust advised:

'... I am extremely sorry for the inconvenience and distress this has caused you...as there have been administration errors on our part, the service has regraded your surgery to urgent in an attempt to reduce the delay in receiving a date for your operation.'

Impact

This case identifies that the patient's complaint was the instigating factor in surgery being expedited. The patient and their GP had previously raised multiple queries requesting information on their waiting list status and had sent multiple additional referrals. However, it was only at the point the patient persevered, and made a complaint, that they were regraded as Urgent.

Personal reflection:

'...I ended up having to get in contact to complain and that's when really things started, I got the operation done last year, so within a year of my letters to the Trust and everybody else, you know... I always said well there's probably other people because of Covid, there's people on the waiting list that need an operation more than I do, but it was my [family member] that had convinced me that I was still entitled to get sorted, so I went ahead and lucky enough, well not lucky enough, I got the operation done a year later. So, it does pay off to do stuff like that and I wouldn't have, it was my [family member] helped me a lot to write these things and see these things...'

Patient D

Case Study 22
Issue: Complaint resulting in additional waiting list information and upgrade in Clinical Urgency

Trust: Western Trust
Medical Specialty: Ophthalmology

Patient I's '*Urgent*' GP referral was downgraded to '*Routine*' and they were not informed.

On 9 June 2018 Patient I contacted the Trust to query how long it would be before they were seen. In response they were informed they had been graded as '*Routine*' and the wait would be up to a year. On the same day Patient I made a complaint to the Trust and contacted their GP who resent the '*Urgent*' referral.

Patient I subsequently brought their complaint to NIPSO.

In response to NIPSO enquiries the Trust advised:

'The second referral received by the Trust was also marked as urgent and the Consultant triaging the referral would have ordinarily triaged and downgraded. However, on this occasion the Consultant retained the urgent status as the patient was unhappy with the delay, and also, to avoid further visits to the GP causing additional stress to the patient. As a result of this an appointment was arranged and the patient attended on 29 July 2018.'

Impact

This case identifies that the patient became aware of the downgrade in their Clinical Urgency solely as a result of their enquiry.

The patient's subsequent complaint, not their clinical condition, also resulted in the upgrade in their Clinical Urgency. Had the patient not made enquiries or complained to the Trust it is unknown when they would have become aware of the downgrade. It is also unlikely that they would have been seen sooner.

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Case Study 23
Issue: Complaint resulting in additional waiting list information and a health professional review appointment

Trust: Northern Trust
Medical Specialty: Physiotherapy Neurology Outpatient team

As previously highlighted within Case Study 9, Patient J was inappropriately referred to Neuro-outpatients physiotherapy, a service which does not accept referrals for Patient J's specific circumstances.

The referral was subsequently returned to the wrong health professional who took no action. Patient J remained unaware they had not been placed on a waiting list.

Some months later, Patient J queried where they were on the waiting list, and consequently became aware they had not been added.

In response to Patient J's subsequent complaint the Trust suggested the implementation of a number of service improvements, alongside an appointment to provide advice and onward signposting '*due to the delay in advising there was no service and in an effort to make amends for the error.*'

Impact

As a direct result of making enquiries, and subsequently a complaint, this patient was notified, not only of an error in their referral, but also of a potential consultation with a specialty who do not review patients with their condition.

Had the patient not raised an enquiry and a complaint, it is unknown when they would have become aware that they had not been placed on a list. It is also unlikely that a specialist appointment would have been arranged or suggested.

As a result of this '*onus*' being placed on individuals to seek out and pursue waiting list information, significant disparity in patient experience has arisen. This is evident in our investigation. It is also evident to many of the Case Study patients who voiced their concerns:

'I think I was fortunate that I did have a bit of insight and could contact and by no means, torture them. I maybe phoned every three, four months. It wasn't like I was phoning every day or anything, but I did do that, and people wouldn't know to do that.'

Patient R

'I'd probably still be on the waiting list if it hadn't been for my [family member] pushing me to push for this. It shouldn't be like that because I would say there'd be a lot of people out there living alone or older who'd sit and wait and hope for the best and that's not really fair on people that are maybe not pushy...'

Patient D

'As patients or the families don't necessarily know how the system should work, the way I do, to follow things up. How many other patients slipped through the net?'

Patient I

'What do other people do? not everybody has someone as thran as me to fight their battles, to fight their case'

Patient G's family member

What waiting list information is currently available without direct contact?

As highlighted within **Chapter One: The Role of the General Practitioner**, some Trusts, at certain intervals, produce general waiting time reports to GPs. Typically, these reports reflect outpatient wait times. As part of this investigation, some Trusts advised our Office of their intention, or current practice, of publishing these reports on their website, thereby making this information available to the public.

It is acknowledged that these steps may potentially improve accessibility of general waiting times to patients, particularly those who are reluctant to contact the Trust directly.

However, this investigation found considerable Trust variation in relation to this practice:

Belfast Trust:

Belfast Trust advised this investigation that it had published a waiting times report on their website in June 2022, with the intention of publishing a '*wider scoped report*' in September 2022. It further advised that it was considering the inclusion of details how to access the report within patient correspondence, including Acknowledgement letters and text messages.

However, following searches of the Trust website, the investigation team were unable to locate the June waiting times report. The only relevant search result was related to waiting times for the fertility service, not wider outpatients.

By way of explanation, the Trust attributed these decisions to a Waiting List Management Unit (WLMU) direction:

'...we have been advised this week to put on hold publishing any waiting list times as this is being handled regionally by the Waiting List Management Unit.'[57]

(refer to **Chapter Nine: Planned Improvements**, for further information).

Northern Trust:

Northern Trust advised that its monthly waiting time report is published on its website

57 Belfast Trust email dated 7 September 2022

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(last available dated December 2022[58]). The investigation team found that the location of this report could be improved, as it is held under a section entitled '*About the Trust*' within a performance section of the website. It is unlikely that patients would know, or attempt, to access this section of the website.

The report can be found at **About the Trust -> Corporate Information -> Our Performance -> Waiting Times Summary Reports. Waiting Times Summary Reports - Northern Health and Social Care Trust (hscni.net)**

Western Trust:

Western Trust advised that it publishes its quarterly waiting time report on its website (last available dated December 2022[59]). Again, the investigation team found that the location of the report could be improved as it is held within two sections, '*Corporate Information*' and under a section entitled '*Information for GPs*' within the 'Services' section of the website. It is unlikely that patients would know, or attempt, to access this section of the website. **Information for General Practitioners (GPs) | Western Health & Social Care Trust (hscni.net)**

Southern Trust:

Southern Trust advised that it produces a waiting time report, but it provided no indication that this was available to members of the public. The investigation team found no evidence to suggest that any waiting time reports are available within the Trust's website.

South Eastern Trust:

South Eastern Trust indicated that it had produced a waiting time report for GPs but it had ceased doing so during Covid. It further indicated that WLMU would 'take this over'.

It does not publish the report on its website.

Although it is welcomed that some Trusts have attempted to make general waiting times available to the public, it is evident that further improvement is required, not only in relation to accessibility but also in raising public awareness that this information is available.

Moreover, the level of variation in Trust approach has again resulted in the potential that some patients may have access to more waiting time information than others, solely dependent on their associated Trust.

Those who are able to complain

Our General Public Survey identified that those respondents who felt able to raise enquiries, and/or complaints, were also faced with considerable barriers, including 69% suggesting that they would like to request information, but they do not know who to contact.

The variation in Trust approach to the provision of Acknowledgements (refer to

58 Last checked 22 March 2023
59 Last checked 22 March 2023

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Chapter Three: Acknowledgements) has likely contributed to this issue.

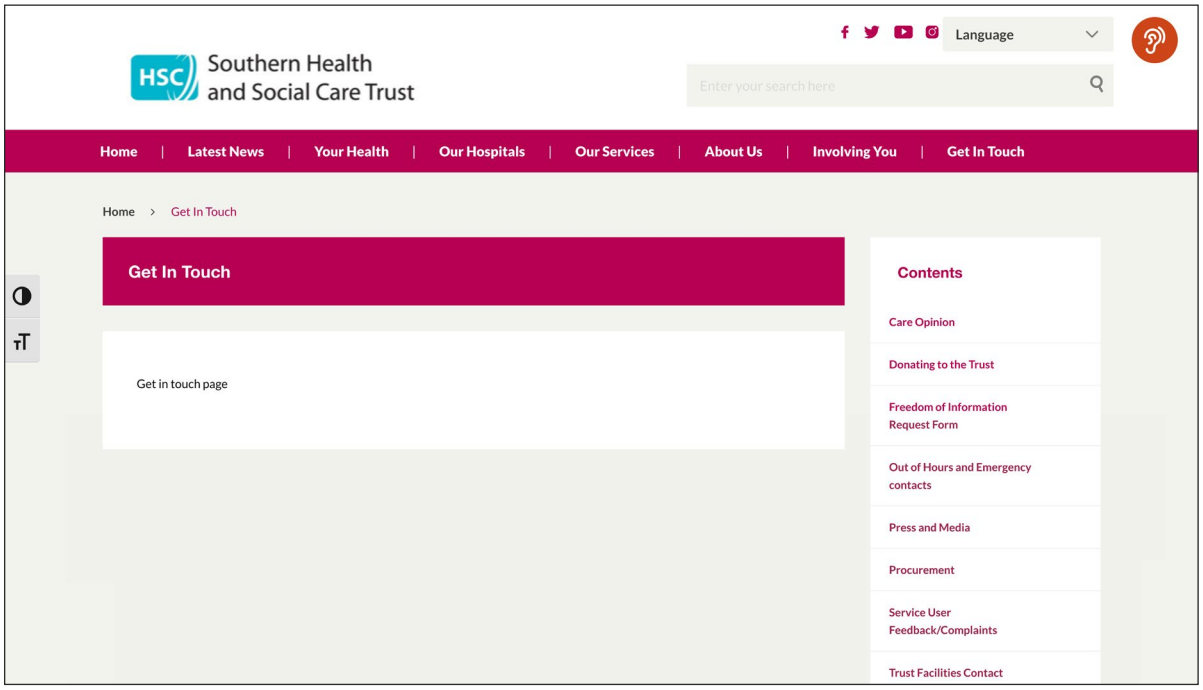
Although it is accepted that these text messages/letters typically contain contact numbers, many specialties have a prolonged history, or continued practice, to not send these to patients.

In addition, the patients who do receive Acknowledgements may be on a waiting list for a considerable period, leading to the likelihood that the letter or text message may be misplaced. The Own Initiative team therefore reviewed Trust websites to assess the accessibility of complaint and enquiry contact information.

Navigating the various Trust websites to access contact details and other information proved to be a convoluted task with a lack of clarity for patients about where waiting list information could be accessed or who they should contact.

Not only was locating information challenging but some of the areas where one would have expected information, were found to be blank or missing information. The following series of screenshots, taken from the Southern and Western Trust websites[60], provide an example of the information reviewed.

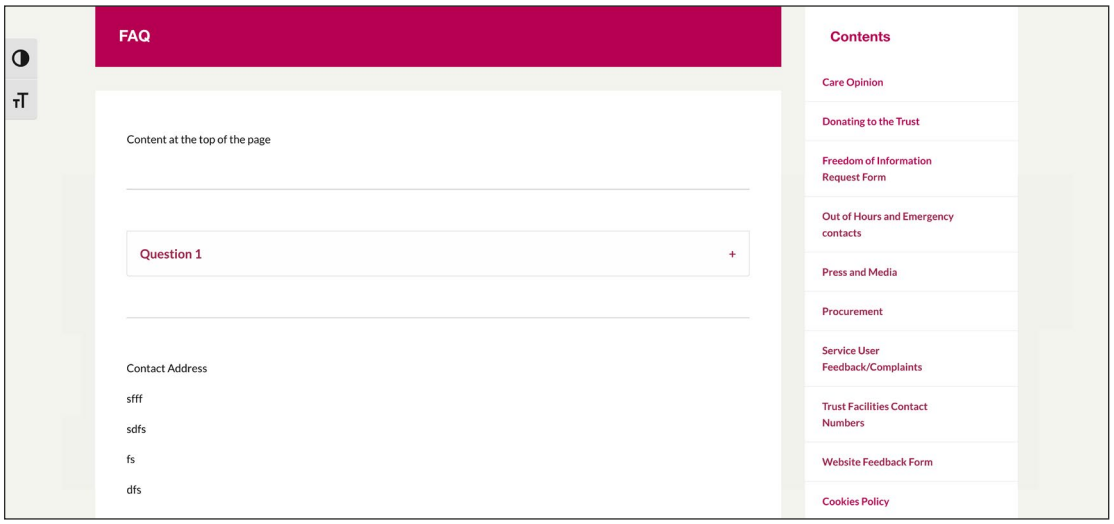
The following screenshot shows the Southern Trust's main webpage for '*Get in touch*', which does not have any content:



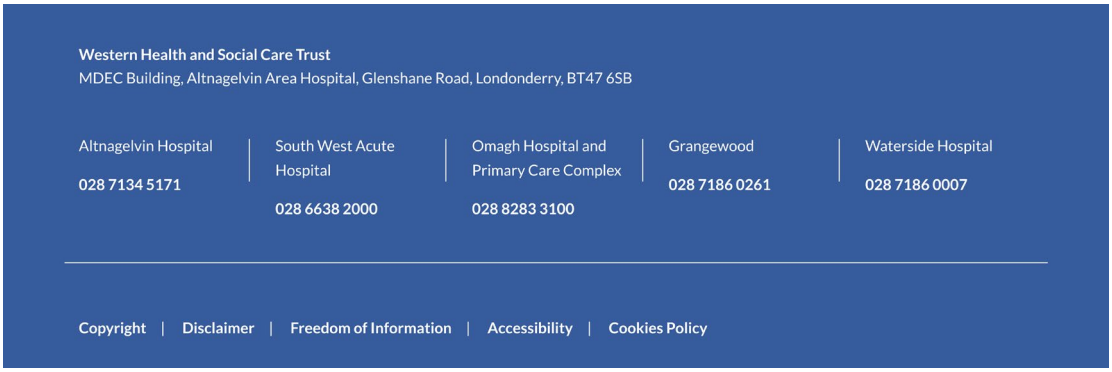
An individual must click on the adjoining banner on the right-hand side of the webpage to access potentially relevant information. For example, the two sections potentially relevant to seeking contact information on waiting lists, and/or related complaints, appear to be '*Service User/Complaints*', and '*FAQ*' (Frequently asked questions).

If an individual subsequently attempts to access information on the '*FAQ*' section of the website they are again faced with an incomplete webpage, without any potential questions or answers.

60 As checked on 17 January 2023



The following screenshot shows the bottom banner of the Western Trusts' website, which like most Trusts, typically lists central hospital numbers.



However, there is no guarantee that a patient will scroll to the bottom of the webpage where these numbers become apparent. There is also no indication or guidance to suggest that these would be the appropriate contact number to access waiting list information.

Although the previous screenshots are limited to two Trust websites, they provide a comparable insight into access issues, highlighting that the process of obtaining relevant contact information is often convoluted and unclear.

Those who did contact

The majority of General Public Survey respondents who identified that they had contacted the Trusts, also suggested that waiting list information was not easily accessible[61], with 24% indicating that they only received information once they had made a complaint.

These issues were mirrored within the individual complaint cases reviewed during the investigation, which identified that individuals must not only feel capable of raising an enquiry or complaint, they must also persevere with their requests.

Many patients/representatives involved in these cases expended considerable resources, raising multiple enquiries/complaints, over a significant period of time. Some contacted not only their Trust, but also their GP; their MLA; and the

61 only 13% of survey respondents indicated that the information was easily accessible

Department. Although all received some form of response to each request, many did not receive the level of information required.

Examples are provided within the following case studies:

Case Study 24
Issue: Perseverance required to access information

Trust: South Eastern Trust
Medical Specialty: Gynaecology

Added to waiting list: October 2016
First Query: March 2017
First Complaint: January 2018
Final complaint response from the Trust (Prior to NIPSO complaint): May 2018 – additional responses provided to Patient MLA Representative in August 2018

Patient R was placed on a waiting list in October 2016, following their diagnosis of Stage IV endometriosis. They were on the waiting list for a period of 4 years until they received their operation in November 2020.

During this time any communication they received regarding their waiting list status, was provided as a direct result of enquiries/complaints made by them, or on their behalf by their GP and MLA.

A small sample of the repeat instances Patient R raised enquiries and/or complaints are provided below:

- **Trust Action 6 October 2016:** Patient attended a clinic appointment and was added to waiting list - No Acknowledgement was sent to patient.
- **Patient initiated Contact: March 2017 Telephone call to Trust** – Patient was informed the consultant aimed to operate within 6 months.
- **Patient initiated Contact: June 2017 Letter to the Trust:** Patient expressed their concern that there had been no review since their diagnosis in June 2016, Patient subsequently received a review appointment in July 2017. Patient was informed timescale would be within the next year.
- **Patient initiated Contact: October 2017 Telephone call to Trust:** Patient was informed that there were 10 urgent cases ahead of them.
- **Patient initiated Contact: December 2017 Telephone call to Trust:** Patient was informed that there was no prospect of surgery in the foreseeable future as surgery had been suspended to prioritise cancer or life threatening conditions. They were also advised that there were still 10 cases ahead of them. No standard letter had been sent to the patient or other patients held on the waiting list to advise them of the cap on the list.
- **January 2018: Complaint submitted to the Trust:** Patient raised a complaint detailing concerns.

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Impact

This case highlights that, with no information being provided as standard, the patient felt they had to repeatedly contact the Trust to gain insight into the progress of their waiting list status.

The level of perseverance required is demonstrated by the multiple contacts the patient made to the Trust during the 14 month period from their first enquiry to the final stage of the Trust's complaint process. Although not illustrated within this case study, this perseverance continued, with Patient R subsequently pursuing their concerns through NIPSO and MLA representation.

The lack of any meaningful communication or update, and the requirement to pursue information themselves, added further distress to Patient R who was already faced with a lengthy waiting list and a complex and worsening condition.

Personal reflection:

'Everything was either a phone call from me to the secretary, a visit to the GP... Every contact I received from them was initiated by me... When you're living with a debilitating condition, where two weeks out of every month, you're struggling to get to work and that's literally all you can do. Each month is a long time. I think even if you could manage people's expectations just to know, "Look, this isn't going to happen for six months, a year." That's still going to be hard. That's still going to be difficult to get through but yes, I think it would definitely help to know.'

Patient R

Case Study 25
Issue: Perseverance Required

Trust: Belfast Trust
Medical Specialty: Gender Identity Services

Added to waiting list: 2 April 2017
First Query: 25 June 2017
First Complaint: 29 March 2018
Final complaint response from the Trust (Prior to NIPSO complaint): 28 April 2018 and 12 March 2019

As previously set out in Case Study 10 in **Chapter Five: 'Fundamental Impact** on Services, Patient K made multiple enquiries and subsequent complaints before the Trust relayed relevant information that had been readily available to the Gender Identity Clinic (GIC) Service.

A small sample of the repeat instances Patient K raised enquiries and/or complaints are provided below:

25 June 2017:
Patient initiated contact with GIC, email:
Patient queried waiting list status and how long they were expected to wait.

27 July 2017:
Patient initiated contact with Belfast Trust Complaints Department, email:
Listed as resolved through phone call and attendance at information session.

29 March 2018:
Patient initiated contact with GIC, email:
Patient queried their position on waiting list and why they were not moving.

29 March 2018:
Patient initiated contact with Belfast Trust, first complaint email:
Patient queried the reason for delay.

20 February 2019:
Patient initiated contact with GIC, email:
Patient queried their position on waiting list and cause for delay with the Service.

22 February 2019:
Patient initiated contact with the Department of Health, email:
Patient raised concern about waiting times.

22 February 2019:
Patient requested assistance from MP, email.

23 February 2019:
Patient and their MP representative initiated contact with Belfast Trust, email & letter:
Request for issues to be considered as a formal complaint.

Impact

This case illustrates the requirement of perseverance, not only to gain access to waiting list progression updates, but also to gain an understanding of why delays are occurring. This undoubtedly added additional stress and frustration to the patient who was already experiencing a lengthy waiting list.

Although it is acknowledged that at each point of contact a response was provided to Patient K, including their position on the waiting list, it is concerning that the onus was repeatedly placed on the patient to access this waiting list information.

It is further concerning that the Service has recently decided to stop providing patients with their waiting list positions, ***'in place of this we will be updating the Brackenburn webpage with live data pertaining to initial appointment timeframes, which can be found at https://bhsct.hscni.net/service/brackenburn-clinic/.'***

The investigation reviewed the updated website, and whilst it is welcomed that additional information has been provided regarding what to expect, alongside potential sources of support, the information remains limited. Rather than advise of average wait times the messaging simply states ***'We are currently seeing people referred up to October 2017.'***[62]

It is therefore disappointing to note that the website now openly discourages contact from waiting list patients, stating:

62 Last checked 9 February 2023

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'If your question relates to waiting times, please do not call the service as we cannot provide any additional information to what is already on this webpage.'

Personal Reflection

'I feel utterly voiceless in this, and would appreciate any and all support that you can offer as member of Parliament...'

Extract taken from Patient K's email to MP

Case Study 26
Issue: Perseverance Required

Trust: South Eastern Trust & Belfast Trust
Medical Specialty: Plastic Surgery

Added to waiting list: 5 January 2018
First Query: 2 June 2018
First Complaint: 2 June 2018
Final complaint response from the Trust (Prior to NIPSO complaint): 8 July 2018

As previously identified in **Case Study 5**, Patient G's family member only became aware of their downgrade in clinical urgency, several months after referral and following multiple contacts to the Trust. The family member compared this contact to *'hitting your head against a brick wall'*. This resulted in the family member attending Trust headquarters in order to seek face to face information. The family member subsequently made complaints to multiple Trusts, as care and treatment was provided by both Belfast Trust and South Eastern Trust.

Although both Trusts eventually accepted the need for improvements, the patient's family member later found that some of these agreed actions had not been implemented, resulting in further perseverance being required.

A small sample of the repeat instances Patient G's family member, or their representative raised enquiries and/or complaints, are provided below:

2 June 2018:
Patient's family member initiated contact with South Eastern Trust: Family member informed of the downgrade in Clinical Urgency and informed that it would be at least 2019 before initial consultation.

3 June 2018:
Patient's family member initiated contact, letter: Patient's family member wrote to their GP; their MLA; the Learning Disability team and the Patient and Client Council (PCC) to inform them of the issue and their complaint to the Trust.

5 June 2018:
Patient's family member initiated contact with South Eastern Trust, email: Patient's family member forwarded completed complaint form to the Trust.

9 June 2018:
South Eastern Trust Contact to Patient's family member: Patient's family member was advised that some aspects of their complaint lie with Belfast Trust – contact details were provided.

22 June 2018:
Patient's family member initiated contact, email, following response from Trust: Patient's family member raised concerns that the Trust had failed to address the content and substance of their complaint.

'If I take the time to list my concerns in detail then please pay my [family member] the courtesy of reading them. If you have read them then you have chosen to ignore them which is equally annoying and frustrating.'

23 June 2018:
PCC initiated contact, email: PCC raised concerns highlighted by the family member.

8 July 2018:
Trust 2nd response to complaint: Trust apologised that initial response did not sufficiently address concerns raised.

12 July 2018:
Patient's family member initiated contact following Trust's complaint response: Patient's family member advised progressing complaint to NIPSO

'You have failed to grasp the nature of my complaint and I am left with no alternative but to seek the help of NIPSO and others in order to resolve the matter.'

Impact

This case identifies how a lack of any regular, meaningful communication or update, and the requirement to pursue information, added further distress to the experience of this patient, and their family, who were already faced with a lengthy waiting list for a complex condition.

Personal Reflection:

'I have rang the number given to me (by SET [South Eastern Trust] for Complaints, Belfast Trust) daily only to be faced with an automated voicemail that they are experiencing high call volumes and to hold the line. I have now rang a total of 6 times (on occasion holding for 20 plus minutes) but no one answers... Please tell me that I will not have to make a complaint about my complaint...'

Patient G's Family Member

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Chapter Eight 'Access to information' Findings

Getting it Right & Being Customer Focused

Maladministration - the Trusts have failed to provide an effective, accessible waiting list information service to patients.

The first principle of Good Administration requires that public bodies provide effective services. The second principle of Good Administration requires that people can access services easily.

The Trusts' failure to provide waiting list information to patients directly has led to significant distress, and potential inequality, by placing the onus on individuals to seek information.

It is recognised, and welcomed, that a small number of individuals advised NIPSO of positive experiences they had with Trust staff regarding the provision of waiting list information. However, the vast majority, identified considerable concerns, including a fear of impact; an inability to raise complaints; the requirement for perseverance; and, at times, evidence of available waiting list information being withheld from patients[63].

These issues are compounded by the Trusts' failure to provide easily identifiable and accessible routes for patients/representatives to access information.

63 *Refer to* Chapter Five: Fundamental Impact on Services

Recommendation 8

The evidence discussed within this Chapter reinforces the requirement for appropriate and regular waiting list communications at the outset (Refer to Recommendation 3).

If regular, relevant information is provided to patients the apparent disparity, between the information/actions afforded to those who feel able to raise enquires/complaints, and those who do not, should be lessened.

However, the ability for patients to access additional information, and to raise concerns, must remain.

8.1 The Department and the Trusts should consider how accessibility to waiting list information can be improved. This should include consideration of:

- Additional reassurance to patients that enquiries and/or complaints will have no impact on their care and treatment;
- Discussion with the Patient Client Council (PCC) on how to improve awareness of their role in supporting individuals to access information – for example inclusion of PCC details within Acknowledgement or update letters to patients; and
- Provision of clear contact information to patients for both waiting list enquiries, and complaints, within individual correspondence.

8.2 The Trust should introduce an accessible area to their websites dedicated to 'Waiting List information', which holds:

- Guidance on what to expect once referred, including expected communications;
- The website address and/or link to the My Waiting Times NI website (refer to **Chapter Nine: Planned Improvements**);
- A copy of the current IEAP;
- All contacts relevant to waiting list information; and
- Alerts regarding the importance of advising of changes in circumstances and contact details.

8.3 The Trusts should provide refresher training – using case study examples provided within this report - to all staff involved in the provision of waiting list information (including complaint staff) to ensure that openness and transparency is at the forefront of all responses.

NIPSO acknowledges that work, which may impact on accessibility of information to patients, is ongoing by the Waiting List Management Unit, and Encompass, which will be discussed further in **Chapter Nine: Planned Improvements**.

Chapter Nine

Planned Improvements

> "Perhaps access to online waiting list using H&SC number but this would probably involve building a new computer system."
>
> ***Patient***

> "It could be a system that I could log into to see an update."
>
> ***Patient***

> "Get an online system that as an individual I can access my data, details, communication etc. Being kept in the dark about my health is archaic and insulting."
>
> ***Patient***

> "How about a website where I can check where I am on the waiting lists? I am on at least four waiting lists across two Trusts, and I have no idea where I am on any of them. How about a website that lists what the average wait times are for all the lists? If I thought I had to wait five years for a particular consultant or operation, I would look at my options for saving up and going private. And I could plan my life better in the meantime!"
>
> ***Patient***

> "Could we not have an online portal where you enter your NHS number to see where you are on waiting lists, etc (with a disclaimer that timeframes are an estimate and subject to change)."
>
> ***Patient***

> "All patients in NI should have an online patient account so that details of the condition and how it affects us can be updated; we can follow the progress of our wait/position on the list on real time rather than waiting for the consultant to write to the GP who then writes to us."
>
> ***Patient***

> "A live dashboard of waiting times should be available for all to view."
>
> ***GP***

> "Rather than placing a large administrative burden on the Trust, it should be possible to access the information online."
>
> ***Patient***

> "Would be beneficial if you could log in online and see where you were on the waiting list."
>
> ***Patient***

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Chapter Nine: Planned Improvements

This chapter focuses on Planned Improvements, specifically the Waiting List Management Unit and Encompass.

In 2018, the Patient and Client Council (PCC) published a report[64] highlighting concerns in relation to waiting list communications. In its conclusion, the report suggested several actions were required, including:

- 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; and
- Regular updating of waiting lists so that they are an accurate reflection of the situation.

It is therefore disappointing that, five years on, as this report has highlighted, these issues and concerns remain.

It is welcomed that in early responses to the investigation, the Trusts acknowledged that Waiting List Communications require improvement. This investigation has already seen some indications that Trusts are beginning to take steps to reflect and improve.

This Chapter will look at two significant projects, highlighted by both the Trusts and the Department as having the potential to improve waiting list communication.

Waiting List Management Unit

In 2021, the Department published its Elective Care Framework '*Restart, Recovery and Redesign*'[65]. The Ministerial Foreword refers to the Framework as being '*a roadmap for tackling the scourge of Northern Ireland's hospital waiting lists.*'

One of the actions contained within the framework was the introduction of a Waiting List Management Unit (WLMU). The main impact of this Unit was stated to be:

'Impact / Potential Impact'

'12.16 The WLMU will have oversight of the elective waiting times, ensuring that patients are managed chronologically and, where necessary, work with Trusts to ensure the transfer of patients across Trust boundaries and to the independent sector [IS]. It will work with Trusts to identify available capacity across Northern Ireland, both in-house and in the IS, and ensure that this capacity is allocated to patients on the basis of their clinical priority and in chronological order...'

Elective Care Framework
'Restart, Recovery, and Redesign' Progress Report, February 2022[66]

64 'Our lived experiences of waiting for healthcare, People in Northern Ireland share their story' PCC March 2018
65 Microsoft Word - HE1 21 377360 Elective Care Framework - Final Version Updated 29 June 2021 to reflect change to Nursing Action (health-ni.gov.uk)
66 doh-elective-care-framework-interim-progress-report-feb-2022.pdf (health-ni.gov.uk)

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It is therefore of note that, in response[67] to the Office's proposal to commence an investigation, the Department, and all Trusts, pointed towards the work of the WLMU:

> *'...The Waiting List Management Unit will be undertaking a specific piece of work to develop standardised waiting time information at Trust and specialty level which will be made available to both patients and GPs. Stakeholder events will be organised to identify the best ways of providing this information in a format which is both accessible, timely and user friendly...'*
>
> **Same statement was included in all Trust responses, March 2022*

During the investigation a number of queries, and meetings, were therefore arranged with the WLMU in order to clarify their role. However, as raised within **Chapter Two: Integrated Elective Access Protocol**, our initial engagement did not provide any reassurance that the WLMU intended to review patient communication.

For example, during the meeting with WLMU in June 2022, although the plan to introduce a patient website was discussed, the WLMU made it clear that its initial priority was the introduction of a waiting times website for GPs.

In addition, the initial responses provided to this Office, failed to provide any reassurance or clarity that patient communication would be within WLMU scope:

> ***'...Whether the WLMU intends to review waiting list communications and introduce a standardised approach?'***

Responses:

> *'Trusts manage their waiting lists in line with IEAP and are best placed to communicate with their patients in relation to their waiting list position as the reasons for wait may vary across and within individual specialties. The Department of Health had been undertaking work with the Patient Client Council to improve and standardise access to waiting time information. Unfortunately this work has not progressed at the pace anticipated due to the unprecedented pressures associated with the pandemic..'*
>
> *SPPG (Formerly HSCB) Response to NIPSOs Strategic Enquiry ahead of the investigation, December 2021*

> *'Going forward, the new Waiting List Management Unit will have a role to play in performance management of Trust implementation of this policy [IEAP] and will undertake (when necessary) site visits or audits to ensure compliance.'*
>
> *Department Letter, November 2021*

67 March 2022

'2) The TOR [Terms of Reference] for the OWG [Operational Working Group] highlighted that the 'Unit will develop a range of monitoring tools and dashboards which will inform discussions with Trusts to identify data quality issues and to monitor adherence to policies and procedures, such as the Integrated Elective Access Protocol (IEAP).'

a. Can the WLMU advise whether any failure to adhere to the IEAP in relation to waiting list communications has been identified?'

Response:

'The WLMU is currently reviewing adherence to IEAP, but it should be noted that the focus of IEAP is about booking processes rather than waiting list communication.'

b. If yes can the WLMU advise what action is being taken?

Response:

[Blank]

WLMU response to NIPSO dated November 2022

It is welcomed that the WLMU subsequently refocused its approach to the waiting times website by working towards one website accessible to both patients and GPs, rather than two separate websites. The '*My waiting time*' website was formally launched by the Department on the 25 May 2023, during finalisation of my report. It can be accessed by clicking **here**.

The Department further advised my office:

'While allowing the outpatient component of the web page to embed, we will be actively seeking feedback on any potential changes which may be required. Information on average waits contained within the website is updated on a monthly basis. In line with NHS England approach, there is a planned expansion of the site to include treatment & diagnostic waiting times and inclusion of specific clinical guidance and advice whilst patients are waiting. The timeframe for the next 2 phases of development in 2023 are as follows:

a. Average Inpatient and Day Case Treatment waits at a specialty level – go live by October 2023;

b. Average Diagnostic waits for CT, MRI, Plain Film and NOUS – go live by January 2024.'

I look forward to review of evidence of these actions, and any subsequent improvements to patient communication.

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Encompass

In response to the Ombudsman's proposal to investigate waiting list communications all Trusts responded with the following suggestion:

'I would suggest you familiarise yourself with the functionality of the new Department of Health 'Encompass' project, which will introduce a digital record for HSC in the coming years, and will include patient portal functionality once implemented.'

Encompass is a Health and Social Care Northern Ireland (HSCNI) wide initiative that will introduce a digital integrated care record to Northern Ireland.

The Trusts currently use multiple computer systems to manage waiting lists, many of which do not communicate with each other. Encompass will move the Trusts to one system which can be accessed, not only by all health professionals, but also by patients/carers themselves. The investigation was advised that South Eastern Trust will be the first to introduce Encompass in November 2023, with full roll out to all Trusts completed by 2025.

This will mean that everyone involved in a patient's care will have secure access to their health and care information from one central record, as and when they need it. Initial work on this initiative commenced in 2018.

'What will the encompass system do?

'The encompass system will be designed and built by our people, for our people.

It's where medical notes will be made, medicines prescribed, tests ordered and referrals made and received. Patients and their carers will be able to book appointments, review test results and correspondence, and communicate with those providing their care

The system will provide real-time, up to date information to all those involved in caring for our patients, empowering them to make efficient, effective, patient-centred decisions.'

Extract taken from a previous post on the Health and Social Care website

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The Own Initiative investigation team met with the organisation who are implementing the Encompass system, and the Department, in February 2023. During this meeting the Own Initiative team had sight of the Encompass '*patient portal*' called '*My Care*'. This will be accessible to patients once they complete registration. Encompass advises that '*My Care*' will allow citizens to have more control of their health care pathway, communications and information.

It is acknowledged, and welcomed, that this initiative is a significant and valuable step towards improving patient accessibility to their own health and care records, as well as standardising the approach of Trusts and specialties.

However, the Encompass system, as it currently sits, will provide limited improvement to the provision of waiting list information to patients. For example:

- ***No individualised information***: The '*My Care*' portal will not provide individualised information on waiting lists – it will not provide patients with their waiting list position, or progression;

- ***No referral outcome***: Although a patient will be able to see that a referral has been made, and to which specialty, they will not be able to review the **outcome** of the referral. There is also no confirmation within '*My Care*' that the referral has resulted in addition to a waiting list or whether the clinical urgency has been changed;

- ***Message facility only available to those who have been seen***: Although patients will be able to message a specialty – this is only available after a patient has been seen or is under the 'care' of a particular team. This function is therefore unavailable to patients who are awaiting a first appointment. Encompass advise that My Care **should** allow patients to raise waiting list specific queries with an appropriate team, however no confirmation has been provided;

- ***Clinic letters available by default***: I welcome that the intent is that clinic letters will be available for patient review by default. However, the Encompass responses to the investigation suggest that this has not yet been agreed through the encompass programme Board. I acknowledge the requirement for safety measures where sensitive information may not be shared with a patient. However, I would suggest that the default should be for the letter to be shared automatically, with the option being available to the health professional to rescind access. Alternatively, if the letters are written specifically to the patient, this would allow for any sensitive information to be withheld from the letter at the outset, with no requirement to prevent access;

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- ***Inability for patients to update all contact information***: Encompass advise that patients will have the ability to update some of their own contact information via '*My Care*' including preferred name, gender, phone number and email address. However additional demographics cannot be edited directly due to regional decisions between Northern Ireland Digital Identity Service and NI Direct programmes. Given the concerns raised within **Chapter Six: Removal from the Waiting List**, having this option available would be a significant step towards reducing did not attends (DNAs), and the need to reinstate patients;

- ***No Acknowledgement letter template***: Although it is welcomed that template letters are expected to be contained within Encompass, and it is anticipated that specialties will not send letters outside of this, an Acknowledgement letter is not currently included within this suite of letters. However, it is noted that ahead of publication of my report the Department agreed the development of the functionality for an "acknowledgement" text.

It is also of note that in response to my draft report, and recommendations, the Encompass team advised:

> *'Waiting list information will not be available within encompass. It is not functionality which is currently available in the Epic system for any of the UK sites who have gone live to date. Encompass is an electronic patient record and has no waiting list management functionality within the system itself.'*

Aside from these limitations, I was particularly concerned to note that little engagement has taken place to make service users/patients aware of Encompass and how to register, etc.

I acknowledge that some work was undertaken with the Patient Client Council (PCC) at the start of 2023 to set up an encompass Engagement Council (eEC). Encompass advise that this is a governance advisory group made up of citizens of Northern Ireland which meets on a monthly basis. They further advise that the council has direct involvement with advising on the rollout plan and getting the message out about its key features.

I also welcome that the week following NIPSO's meeting with Encompass, the South Eastern Trust – who are planned to be the first Trust to roll out Encompass in Autumn of this year – tweeted a message and video to promote the introduction of Encompass.

However, I would have expected that plans for patient engagement, and public awareness, would have progressed further than has been suggested.

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Chapter Nine 'Planned Improvements' Findings

Whilst the Waiting List Management Unit and Encompass have potential to improve waiting list communications and access to information for patients there are a number of areas where they could be improved. Overall, they are positive developments and of significant importance.

I also note that following review of my draft report the Encompass team advised that its Communications team is planning wider engagement with identified stakeholder groups including professional bodies, voluntary organisations service user groups and local representatives. They state that a detailed stakeholder mapping process had been completed and an agreed strategy and action plan will be finalised in the weeks to come.

It has also been highlighted that a Communication and Engagement plan has been devised for the '*My Waiting times*' website with a publicity campaign using social media across all HSC social platforms and an email engagement with stakeholders.

We look forward to review of progress on these developments within the Department and Trusts Action plans.

I would however, continue to encourage the Department and Trusts to take advantage of this early stage of implementation to consider the issues raised in this investigation.

Recommendation 9

The Department should:

9.1 Clarify the role of the WLMU in regard to the improvement of patient communication – in doing so the Department should consider the findings within this report, and consider whether implementation of some of the recommendations would be best placed within the remit of WLMU;

9.2 Consider the limitations of Encompass discussed within this Chapter, and identify potential solutions – this consideration should include an update to Encompass to allow:

- Patients to see the outcome of their referral;
- Patients to raise waiting list specific queries with an appropriate team;
- The inclusion of an Acknowledgement template and;
- Agreement that clinic letter should be available to the patient by default.

9.3 Take additional steps to provide greater clarity on the role of WLMU, and the planned introduction of Encompass, to the general public. Consideration should be given to the placement of additional advice on both of these areas of work within the previously recommended 'waiting list information section' of each Trust website.

Chapter Ten

Conclusion

"If they followed their own policy, and common sense, it would have worked."

Patient

"Anything that has come out of this that helps other people get some communication, and know that they're actually on a waiting list, and they don't have to go through what I did."

Patient during NIPSO interview

"It's a privilege to maybe, be able to try and improve it for other people. So, no. I think it's great you're doing it because if there's anything I can do to help, I would love to be able to help improve it."

Patient during NIPSO interview

"I don't want to sound like I'm knocking the Trusts, I don't think that anyone's setting out to do a bad job here, it's just that it is a complex area with lots of moving parts and interfaces but there is really maybe a lack of central direction about a lot of this. It's just been left to grow organically until it's like a field full of weeds, and that makes it difficult to tackle it because, you concentrate on this corner of the weeds, this corner of the weeds..."

GP

"It was just good to help, if I can help other people, so they haven't to go through the same thing that I went through."

Patient during NIPSO interview

"It speaks volumes about an organisation in terms of leadership and how information's passed from the top to the bottom, or even how change is implemented from the bottom up, and how people are encouraged to innovate and develop new ways and then transfer those new ways right across the whole piece so that it works better or things are learnt, but that doesn't seem to happen."

GP

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Chapter Ten: Conclusion

This chapter provides a brief summary on the overall findings of the report.

This investigation report has set out the evidence and detailed analysis of how the Department of Health and the Health & Social Care Trusts have failed to meet their obligations in relation to the management of waiting list communications with patients.

The waiting list communication landscape is one which has become increasingly fractured and complex. Information is held on multiple IT systems and practice varies considerably both across, and between, Trusts. Waiting list communication, as experienced by patients, is incomplete, difficult to access, and leaves them without vital information to manage and make decisions about their health and care needs. This has led to patients, and their families, experiencing significant frustration, distress and anxiety, and in some cases, mismanagement of their healthcare.

It further has become a source of both additional work and frustration for many GPs who have also acknowledged their inability to fully access the system or indeed to be kept up to date with the waiting list journey of their patients.

Overall, this investigation has found a waiting list system which is in disarray and sometimes even chaos. There is a lack of coherence between the different parts of the system, a lack of clear communication, and a lack of an overall agreed plan for improvement. On this basis, and those of repeated failures in many parts of the system, I make an overall finding of systemic maladministration and would urge the Department to work more cohesively with the Trusts, GPs and patient representatives to address the need for improvement.

I acknowledge that this work will be undertaken within a financially challenging environment, which has been compounded by the 2023-24 budget announcement identifying a funding gap of £732 million for Health and Social Care Services this financial year[68].

I therefore give a commitment that I will fully consider any financial and/or logistical reasoning put forward by the Department and/or the Trusts as to why any of my recommendations cannot be implemented as intended, alongside any alternative action they suggest. 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.

Recommendation 10

10.1 I recommend that a working group, with representatives from each of the Trusts and the Department, is established to take forward implementation of my recommendations. This group should promote shared learning across the Trusts and help facilitate the move towards a standardised approach to waiting list communications. Meetings should be held monthly, with minutes of the meetings being shared with my office.

10.2 I further request that an outline action plan is provided to my office within three months of the date of my report's publication. A comprehensive update on the progress made against each recommendation should then be provided nine months later, a year following publication.

68 Department response to NIPSO 26 May 2023

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"Feel like I've been forgotten and my life means nothing to anyone."
"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."
"I want the pu... know just ha... my fianc... the p..."
"Forgott... left in... wa..."

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Appendix One

The Principles of Good Administration

Principles of Good Administration

Good administration by public service providers means:

1. Getting it right

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

2. Being customer focused

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to its commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances.
- Responding to customers' needs flexibly, including, where appropriate, co- ordinating a response with other service providers.

3. Being open and accountable

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.
- Stating its criteria for decision making and giving reasons for decisions.
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for its actions.

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4. Acting fairly and proportionately

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

5. Putting things right

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

6. Seeking continuous improvement

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.

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Appendix Two

Terms of Reference

Terms of Reference for the Own Initiative Investigation

Background

The Northern Ireland Public Services Ombudsman (the Ombudsman) has launched an Own Initiative[1] investigation into the Department of Health's (the Department), and the Health and Social Care Trusts' (the Trusts), administration of communications to patients and/or their carers when placed on healthcare waiting lists.

The investigation will focus on the current processes undertaken to communicate waiting list information, alongside the content and regularity of these communications, from the point of a referral being received by a Trust until an appointment/procedure date is booked and attended.

Purpose of the Investigation

The Ombudsman's investigation into the administration of waiting list communications is being conducted in accordance with Section 8 of the Public Services Ombudsman (Northern Ireland) 2016 Act (the Act).

The purpose of the investigation is to ascertain if there is systemic maladministration[2], or systemic injustice[3] as a result of the exercise of professional judgement in how the Department, and the Trusts, manage and provide information/communications to patients and/or their carers about their waiting list status.

The investigation will seek to identify whether or not there are recurring issues with communication or whether any identified issue, left unchanged, could potentially impact on a number of individuals in the future. The Ombudsman may make recommendations should she identify systemic maladministration or systemic injustice within her investigation.

Scope of the Investigation

The Ombudsman will examine the actions of the Department, and the Trusts, in administrating communications to those placed on waiting lists with a particular focus on:

- The standard communications provided to individuals once placed on a waiting list and the subsequent regularity of updates and information provided; and
- The accessibility of waiting list information.

1 The term 'Own Initiative' is derived from the ability of the Ombudsman to proceed with a systemic investigation with no requirement for a complaint to have been made.
2 Maladministration is not defined in the legislation, but is generally taken to include decisions made following improper considerations, action or inaction; delay failure to follow procedure or the law; misleading or inaccurate statements; bias; or inadequate record keeping. 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.
3 Injustice is also not defined in legislation but can include upset, inconvenience, or frustration.

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The objectives of the investigation are to:

- Evaluate the effectiveness of Waiting List Communication processes/policy and whether they are consistently applied across the Trusts;
- Evaluate the content of standard waiting list information provided to patients and/or their carers;
- Gather and examine patient/carer experiences of communication when placed on a waiting list and the impact this has on their health and wellbeing and/or care and treatment;
- Gather the perceptions of General Practitioners on the effectiveness of waiting list communications provided by the Trusts; and
- Identify good practice within Waiting list communications and make recommendations for improvement where required.

In determining whether systemic maladministration has occurred the Ombudsman will test the actions of the Department and the Trusts against the framework of the Principles of Good Administration[4] (Appendix 1).

In conducting her investigation the Ombudsman has the same powers as the High court to request information and the production of documents relevant to her investigation.

Reporting

The Ombudsman will publish interim updates on the progress of her investigation. At the conclusion of her investigation the Ombudsman will also publish a report of her investigation on her website **www.nipso.org.uk** and will lay a copy before the Northern Ireland Assembly.

Compliance/Follow Up

If recommendations are made within the investigation report, the Ombudsman's Own Initiative team will regularly engage with the Department, and the Trusts, following publication, to review and assess implementation. The Ombudsman may consider the publication of follow up reports to raise public awareness of the steps taken by the Department and the Trusts to action the recommendations.

4 Parliamentary and Health Service Ombudsman (2009) *Principles of Good Administration*

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Appendix Three

General Public Survey (blank copy)

Welcome to NIPSO's survey on Waiting list Communications

The Northern Ireland Public Services Ombudsman (NIPSO) is carrying out an investigation into how the health service communicates with patients and their carers regarding their status on waiting lists. As part of this investigation we are keen to hear the experiences of patients and/or their carers who have been placed on a waiting list. Further information on the investigation is available on our website **nipso.org.uk/finding_type/own-initiative-investigations**

The survey will take approximately 8 – 10 minutes to complete. Submissions will close on **29 July 2022**

Our **privacy notice** lets you know what happens to any personal data that you give to us, or any that we may collect from or about you.

Should an alternative language or format be required, or should you require assistance from a member of our staff to complete the survey, please contact **ownintiative@nipso.org.uk** or **028 9033 6773**

Thank you for taking the time to complete this survey.

Section 1 – About you

This section will ask general questions about you.

1. Are you answering for yourself or on behalf of someone else?

☐ Myself ☐ Someone else

2. Which age group applies to you?

☐ 0-17 ☐ 18-34
☐ 35-54 ☐ 55-74
☐ 75+

3. Do you require additional assistance/ adjustments when communicating with the Health and Social Care Sector?

☐ Yes ☐ No

4. If yes, please specify

☐ Translation/Interpretation
☐ Larger text
☐ Braille
☐ Other – (please specify)

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Section 2 – Waiting List

This section will ask more specific questions around the waiting list on which you are/were placed.

5. In which Health and Social Care Trust are/were you on a waiting list?

- ☐ Belfast
- ☐ Northern
- ☐ South Eastern
- ☐ Southern
- ☐ Western
- ☐ Don't know

6. Which of the following best describes the type of waiting list on which you were placed?

- ☐ Cancer Services
- ☐ Diagnostic test
- ☐ Admission for treatment or surgery
- ☐ A first consultant led outpatient appointment
- ☐ Don't know
- ☐ Other - (please specify)

7. What condition are you placed on a waiting list for? Alternatively, if known please provide the service area, for example Neurology/ Orthopaedics, etc.

8. How long have you been, or were you, placed on this waiting list (an approximate timeframe can be provided)?

- ☐ 0-3 months
- ☐ 3-6 months
- ☐ 6-12 months
- ☐ 1 – 2 years
- ☐ More than 2 years
- ☐ Not sure
- ☐ Other – please specify

Section 3 – Routine Communication

This section asks questions about the routine information and updates given to you following your placement on a waiting list. Please only think about information that was provided to you without you having to request it.

9. Did you receive any waiting list communications other than an invitation to make a booking/ appointment?

- ☐ Yes
- ☐ No
- ☐ Don't know

10. If yes, who provided you with waiting list communications?

- ☐ GP ☐ Trust
- ☐ Both GP and Trust
- ☐ Other (please specify)

11. If you received waiting list communications, did one or more contain the following:

	Yes	No	Don't Know
Confirmation of the date you were added to the waiting list	☐	☐	☐
Your position on the waiting list	☐	☐	☐
Average waiting times	☐	☐	☐
Anticipated timeframe for your appointment/procedure	☐	☐	☐
Your Clinical Urgency for example – urgent, routine.	☐	☐	☐
Contact details to access updates and advise of changes in circumstances	☐	☐	☐
Advice on when to expect updates	☐	☐	☐
Advice on what to do if your condition has changed	☐	☐	☐
Advice on what to do and what will happen if you are unable to attend an appointment	☐	☐	☐
A request to identify your availability for cancellation/short notice appointments	☐	☐	☐
Information on how to request the communication in a different format for example different language/larger font	☐	☐	☐
Supporting information to help you manage your condition while waiting for care	☐	☐	☐

Further comment if necessary:

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12. Thinking about the communications, or lack of communications, provided to you whilst on the waiting list, to what extent do you agree with the following statements?

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree	N/A
I have been kept informed about what is happening with my care	☐	☐	☐	☐	☐	☐
The communications were clear and easy to understand	☐	☐	☐	☐	☐	☐
The communications provided sufficient information	☐	☐	☐	☐	☐	☐
The communications were provided in a format suitable to my needs	☐	☐	☐	☐	☐	☐
I was provided with regular updates	☐	☐	☐	☐	☐	☐
I consider that the communications provided to patients on healthcare waiting lists needs to be improved	☐	☐	☐	☐	☐	☐

13. If you were not provided information in a format suitable to your needs, please provide further detail:

14. At any time during your wait were you contacted to ask if you still required your appointment?

- ☐ Yes
- ☐ No
- ☐ Don't know

15 Who do you think is/should be responsible for the providing routine waiting list information and updates to patients?

- ☐ GP
- ☐ Trust
- ☐ Both GP and the Trust
- ☐ Don't know
- ☐ Other – (please specify)

16. Do you consider that regular waiting list updates should be provided by the Trust to patients and/or their GPs?

Yes, updates should regularly be provided to the patient	☐
Yes, updates should regularly be provided to the GP who can update their patient	☐
Yes, updates should regularly be provided to both the patient and their GP	☐
No	☐
Don't know	☐

17. If yes, which of the following do you consider should be included within waiting list communications, multiple options may be chosen:

	Within the 1st communication	Within updates
All options below	☐	☐
Confirmation of the date you were added to the waiting list	☐	☐
Your position on the waiting list	☐	☐
Average waiting times	☐	☐
Anticipated timeframe for your appointment/procedure	☐	☐
Your Clinical Urgency for example – urgent, routine.	☐	☐
Contact details to access updates and advise of changes in circumstances	☐	☐
Advice on when to expect updates	☐	☐
Advice on what to do if your condition has changed	☐	☐
Advice on what to do and what will happen if you are unable to attend an appointment	☐	☐
A request to identify your availability for cancellation/ short notice appointments	☐	☐
Information on how to request the communication in a different format for example different language/ larger font	☐	☐
Supporting information to help you manage your condition while waiting for care	☐	☐

Is there anything additional you consider should be provided?

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Section 4 – Communication following request

This section focuses on the waiting list information you received following a request or complaint from you or from someone on your behalf.

18. Did you (or someone on your behalf) request information/ update on your position on the waiting list?

☐ Yes ☐ No

19. Do you typically access waiting list updates through your GP?

☐ Yes ☐ No

If no, please advise where updates are accessed

20. If you, or someone on your behalf, requested information on your waiting list status to what extent do you agree with the following statements:

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree	N/A
It is my responsibility to request information on my waiting list status	☐	☐	☐	☐	☐	☐
Information about my waiting list status was easily accessible	☐	☐	☐	☐	☐	☐
I was satisfied with the level of information provided to me	☐	☐	☐	☐	☐	☐
I only received information on my waiting list status once it was requested	☐	☐	☐	☐	☐	☐
I only received information on my waiting list status once I made a complaint	☐	☐	☐	☐	☐	☐
I was unable to access information in relation to my waiting list status	☐	☐	☐	☐	☐	☐

21. If you have not requested information on your waiting list status to what extent do you agree with the following statements:

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
I do not consider it necessary to access information on my waiting list status	☐	☐	☐	☐	☐
I am satisfied that I am provided with enough information on my waiting list status without the need to make contact	☐	☐	☐	☐	☐
I would like to request information but I do not know who to contact	☐	☐	☐	☐	☐
I remain unaware whether I have been placed on a waiting list	☐	☐	☐	☐	☐
I do not want to put additional pressure on the health service by requesting information	☐	☐	☐	☐	☐
I do not feel able to request information	☐	☐	☐	☐	☐
I feel unable to complain or request information as I fear it may jeopardise my future treatment	☐	☐	☐	☐	☐

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Section 5 – Impact

This section of the survey focuses on how communication, or a lack of communication has impacted on your health and well being and/or your care and treatment.

22. Thinking about the communications, or lack of communications, provided to you whilst on the waiting list, to what extent do you agree with the following statements?

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree	N/A
Receiving regular updates reassured me that my care was being progressed	☐	☐	☐	☐	☐	☐
Accessing information about my waiting list status causes me distress and frustration	☐	☐	☐	☐	☐	☐
I struggled to access information about my waiting list status	☐	☐	☐	☐	☐	☐
I feel like I have been forgotten about	☐	☐	☐	☐	☐	☐
I have been provided with the right information to care for myself, or I have been able to access it easily	☐	☐	☐	☐	☐	☐
My circumstances changed while on the waiting list and I was unaware who to contact	☐	☐	☐	☐	☐	☐
If I had been fully informed about the extent of waiting times I may have considered private treatment	☐	☐	☐	☐	☐	☐
I have been listened to and taken seriously	☐	☐	☐	☐	☐	☐

23. Do you feel that the waiting list communication (or lack of) provided to you has had an impact – either positive or negative?

- ☐ Positive impact
- ☐ Negative impact
- ☐ No impact

If impacted, please provide details below:

24. Did a lack of information contribute to you being unprepared for a procedure/ appointment, leading to a delay or cancellation?

- ☐ Yes
- ☐ No
- ☐ Don't know

If yes, please provide details below:

25. Did a lack of information lead to mismanagement of your care and treatment? For example was there a delay in your placement on a waiting list; were you discharged from a waiting list without being informed?

- ☐ Yes
- ☐ No
- ☐ Don't know

If yes, please provide details below:

26. The Clinical Urgency (Red flag/Urgent/ routine) recommended by the Health professional (for example your GP) who referred you to the waiting list may be changed by the Trust.

Thinking of the Clinical Urgency of you/their referral which of the following statements apply:

- ☐ I was not aware the Trust could change the Clinical Urgency recommended by my referrer
- ☐ I am not aware of what Clinical Urgency I was placed on the waiting list
- ☐ I was made aware of the Clinical Urgency I was placed on the waiting list
- ☐ Other (please specify)

27. If the Clinical Urgency of your referral (Red Flag/Urgent/Routine) was changed by the Trust, do you consider that a lack of communication around this change had a negative impact on your care and treatment?

- ☐ Yes
- ☐ No
- ☐ N/A

Please provide comment below:

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Section 6 – Improvements/Good Practice

This section of the survey asks if there are areas where you have experienced good communication or if there are improvements you think need to be made to waiting list communications.

28. Have you experienced an example of good communication while placed on a waiting list?

- ☐ Yes
- ☐ No

If yes, please provide further details below:

29. Do you have any additional information about your experience with waiting list communications which you would like to share, including suggestions as to how it could have been done better?

30. What preferred formats of communication do you feel would be most appropriate to provide updates to patients on their waiting list status?

- ☐ Telephone
- ☐ Text
- ☐ Email
- ☐ Letter
- ☐ Other

If other please specify:

31. Would you be willing to share your experience in more detail with NIPSO?

- ☐ Yes
- ☐ No

If yes, please provide contact details below:

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Appendix Four

General Practitioner (GP) Survey (blank copy)

GP Survey - Waiting List Communications

1. In which Health and Social Care Trust is your General Practice / the General Practice where you work?

- ☐ Belfast
- ☐ Northern
- ☐ South Eastern
- ☐ Southern
- ☐ Western

2. Which Health and Social Care Trust do you deal with most regularly?

- ☐ Belfast
- ☐ Northern
- ☐ South Eastern
- ☐ Southern
- ☐ Western

3. How do the Trusts provide you with waiting list information? (Please tick all that apply)

- ☐ None of the above
- ☐ Regular Bulletins
- ☐ Public Website
- ☐ Website available to GPs
- ☐ Data sharing system (for example Clinical Communication Gateway (CCG))
- ☐ Letter
- ☐ Email
- ☐ Other (please specify)

4. How effectively do you consider each Trust communicates with you/your practice in relation to waiting lists?

	Very effectively	Somewhat effectively	Not so effectively	Not at all effectively	N/A
Belfast	☐	☐	☐	☐	☐
Northern	☐	☐	☐	☐	☐
South Eastern	☐	☐	☐	☐	☐
Southern	☐	☐	☐	☐	☐
Western	☐	☐	☐	☐	☐

5. Are you familiar with the Integrated Elective Access Protocol (IEAP)?

☐ Yes ☐ No

6. If yes, are you aware of the areas within the IEAP which reference Trust communication with GPs and/or their patients?

☐ Yes ☐ No ☐ N/A

Provide comment if necessary

7. Are you aware that the 2008 IEAP was recently updated? (available here)

☐ Yes ☐ No

8. Please indicate which of the following information is typically provided to GPs by the Trust, or is easily accessible, following referral of a patient to a waiting list (multiple options may be chosen)

- ☐ None of the above
- ☐ Receipt/confirmation referral has been received/read (CCG)
- ☐ Receipt/confirmation referral has been received/read (via letter or email)
- ☐ Confirmation a patient has been added to a waiting list
- ☐ Individualised updates on expected wait times
- ☐ General wait times per waiting list
- ☐ Confirmation of Clinical Urgency i.e. routine, urgent, etc
- ☐ Direct contact details for the administrator of the waiting list, should updates be required
- ☐ Other (please provide detail)

9. Please indicate which of the following information you consider should be provided to GPs and/or the patient by the Trust, following referral of a patient to a waiting list (multiple options may be chosen)

- ☐ Receipt/confirmation referral has been received/read
- ☐ Confirmation a patient has been added to a waiting list
- ☐ Individualised updates on expected wait times
- ☐ General wait times per waiting list
- ☐ Confirmation of Clinical Urgency i.e. routine, urgent, etc
- ☐ Direct contact details for the administrator of the waiting list, should updates be required
- ☐ None of the above
- ☐ Other (please provide detail)

10. If general wait times are provided/ accessible to GPs, in your experience, is the information regularly updated?

- ☐ Yes
- ☐ No
- ☐ Don't know

Please provide detail

11. Do you use Clinical Communication Gateway (CCG) for Trust referrals?

☐ Yes ☐ No

If you do not use CCG can you comment why this is the case?

12. Do you regularly check CCG to identify if a referral has been received and read?

☐ Yes
☐ No - I do not use CCG
☐ No - it is not within my role to confirm receipt
☐ Other (please specify)

13. If a patient's referral is downgraded/ upgraded (for example Urgent to Routine) once received by the specialist/service area, are you informed of this?

☐ Yes - on every occasion
☐ Yes - but not on every occasion
☐ Yes - only if related to a Red Flag
☐ Yes - only if related to suspected cancer
☐ No

If no, do you consider that GPs and/or patients should be informed?

14. Do you consider that GPs and/ or patients should be informed of changes to the clinical urgency of their referral?

☐ Yes - GPs and patients should be informed
☐ Yes - GPs should be informed
☐ Yes - patients should be informed
☐ No

15. In your experience, do GPs refer a patient to multiple sites/Trusts – for example would you send a referral for an ENT consultation for one patient to more than one Trust or more than one ENT Department?

☐ Yes - often
☐ Yes - occasionally
☐ No

If necessary, please provide comment on your answer choice

16. To what extent do you agree with the following statements:

	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree
The Trusts current system for communicating waiting list information to GPs is effective	☐	☐	☐	☐	☐
GPs should be provided with regularly updated, meaningful waiting list information	☐	☐	☐	☐	☐
Waiting list information is easily accessible to GPs	☐	☐	☐	☐	☐
Trusts should communicate waiting list information directly to patients	☐	☐	☐	☐	☐
Waiting list information is easily accessible to patients	☐	☐	☐	☐	☐
The waiting list information provided to patients by the Trust is inadequate	☐	☐	☐	☐	☐
If you wish to make further comment on your choices, please provide below:	☐	☐	☐	☐	☐

17. Have you/your practice ever made a complaint to the Trust about the availability/provision of waiting list information?

- ☐ No - I have not felt it necessary to do so
- ☐ No - I do not know who to complain to
- ☐ Yes

If you wish to provide further comment please provide below:

18. Please indicate which of these statements is reflective of your approach to waiting list communications?

- ☐ I do not provide waiting list information to patients - it is not within my role to do so
- ☐ I only provide general waiting time information at the point of referral
- ☐ I provide regular updates to patients on their waiting list status as a matter of routine
- ☐ I provide updates on waiting list status when patients contact the surgery
- ☐ Other (please provide further detail)

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19. Do you routinely advise patients what clinical urgency you have placed on their referral (e.g. Routine, Urgent, Red Flag)?

- ☐ Yes
- ☐ No
- ☐ Only if Red Flag
- ☐ Only if suspected cancer

20. How often do patients contact you to receive an update on their waiting list status?

- ☐ Never
- ☐ Rarely
- ☐ Occasionally
- ☐ Frequently

If you wish to provide further detail on your answer, please provide below:

21. To what extent do you agree with the following statements:

	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree
GPs do not have a role in providing waiting list information to patients	☐	☐	☐	☐	☐
A GPs role in waiting list communications is only to provide general waiting time information at the point of referral	☐	☐	☐	☐	☐
It is the Trust's responsibility to provide patients with information on their waiting list status	☐	☐	☐	☐	☐
GPs are unable to provide meaningful updates to patients on their waiting list status	☐	☐	☐	☐	☐
Providing waiting list information to patients places a significant strain on GP resources	☐	☐	☐	☐	☐

If you wish to make further comment on your choices, please provide below:

22. Do you consider that the current system for communicating waiting list information to GPs should be improved?

- ☐ Yes – major improvements are required
- ☐ Yes – minor improvements are required
- ☐ No – improvements are not required
- ☐ Unsure

If yes, have you any further comments or recommendations which may be useful?

23. Do you consider that the current system for communicating waiting list information to patients should be improved?

- ☐ Yes – major improvements are required
- ☐ Yes – minor improvements are required
- ☐ No – improvements are not required
- ☐ Unsure

If yes, have you any further comments or recommendations which may be useful?

24. Are you aware of any current Department of Health/Trust plans to improve the waiting list communications provided to GPs and/or their patients?

- ☐ Yes
- ☐ No

If yes, please provide comment

25. In your experience, do current deficiencies in waiting list communications have a negative impact on patients?

- ☐ Yes
- ☐ No
- ☐ Don't know

Please comment/provide examples if applicable

26. If Trusts acknowledged receipt of all referrals to patients and GPs do you consider that this would reduce potential mismanagement/inaction of referrals?

- ☐ Yes
- ☐ No
- ☐ Don't know

If you have had experience of mismanagement as a result of a lack of acknowledgement please comment/provide examples

27. If Trusts do not routinely inform GPs/ patients when the clinical urgency of a referral is changed, could this potentially have a negative impact on the patient and/or their care?

- ☐ Yes
- ☐ No
- ☐ Don't know

Please provide examples/comment if a patient has experienced negative impact as a result of not being informed

28. In your experience has a lack of waiting list communication ever been a factor in a patient being unprepared, or no longer requiring, an appointment/surgery?

- ☐ Yes
- ☐ No

If yes, please provide further detail and/or examples where available:

29. In your experience, do Trusts take steps to validate addresses prior to sending out appointment letters to patients where a significant period of time has lapsed since the referral was made?

- ☐ Yes
- ☐ No
- ☐ Don't know

If you have examples where a lack of validation of address/contact information has cause an issue please detail

30. Do you consider that effective communication with patients regarding waiting lists would lead to reduced pressure on the Health Service?

- ☐ Yes
- ☐ No

Please explain:

31. In your experience, are there Trusts/specialties/service areas which are better at communicating information regarding waiting lists than others?

☐ Yes
☐ No

If yes, please provide further detail

32. Would you be willing to speak in further detail with NIPSO?

☐ Yes
☐ No

If yes, please provide contact details

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