

Annual Report 2021



Patient
Advocacy
Service

INFORMATION | SUPPORT | EMPOWERMENT

Contents

	Foreword	2
1.	Patient Advocacy Service Highlights	4
2.	Our Remit	5
2.1	Patient Advocacy Service Remit.....	6
3.	Our Service	8
3.1	Responding to Covid-19's Ongoing Impact.....	9
3.2	Our Work in 2021.....	9
3.3	Complexity of Work by Our Service.....	12
3.4	Key Issues for Our Service.....	12
4.	Our Standards Work	15
4.1	Ongoing Development of the Patient Advocacy Service.....	16
5.	Our Policy Work	17
5.1	Stakeholder engagement.....	18
5.2	Public Consultations and Submissions.....	18
6.	Promoting Our Service	19
6.1	Promotion Work.....	20

Foreword

2021, the second year of the Covid-19 pandemic, was another hugely challenging year for everyone in our society. However, the pandemic, its restrictions, and ongoing disruptions to healthcare services in Ireland continued to have a particularly detrimental impact on the people supported by the Patient Advocacy Service.



The Patient Advocacy Service, commissioned by the Department of Health and delivered by the National Advocacy Service for People

with Disabilities (NAS), provides support to people who wish to make a complaint to the HSE about their care in a Public Acute Hospital or a HSE operated Nursing Home. In just its second full year of operation, the Patient Advocacy Service continued to face several challenges as hospitals and their staff responded to the changing guidelines around the Covid-19 pandemic, resulting in restrictions on visiting, staff shortages, meetings postponed, and delays across the complaints process. During this period people experienced traumatising and life changing events and the Patient Advocacy Service witnessed first-hand the positive impact advocacy, provided by our Service, made to these people during these difficult times.

The Patient Advocacy Service continued to operate as normal during 2021, with our staff working remotely and demonstrating professionalism, determination, empathy, and innovation to embrace all forms of communication

available, such as online technologies, to support people across Ireland to uphold their human rights and support them to have their views and complaints heard.

Despite the difficulties presented by the Covid-19 pandemic, the Patient Advocacy Service continued to build its capacity and effectiveness to ensure continued complaints advocacy to people across Ireland. In February 2021, the initial term of the Patient Advocacy Service contract was extended by a period of 16 months, from June 2021 to the end of October 2022. The Patient Advocacy Service also signed a Memorandum of Understanding with the HSE outlining their joint commitment to further improve support services for people who wish to make a complaint about the care they have received in public acute hospitals. The remit of the service was also extended to include support for people in HSE-operated nursing homes wishing to make a complaint about care they have received.

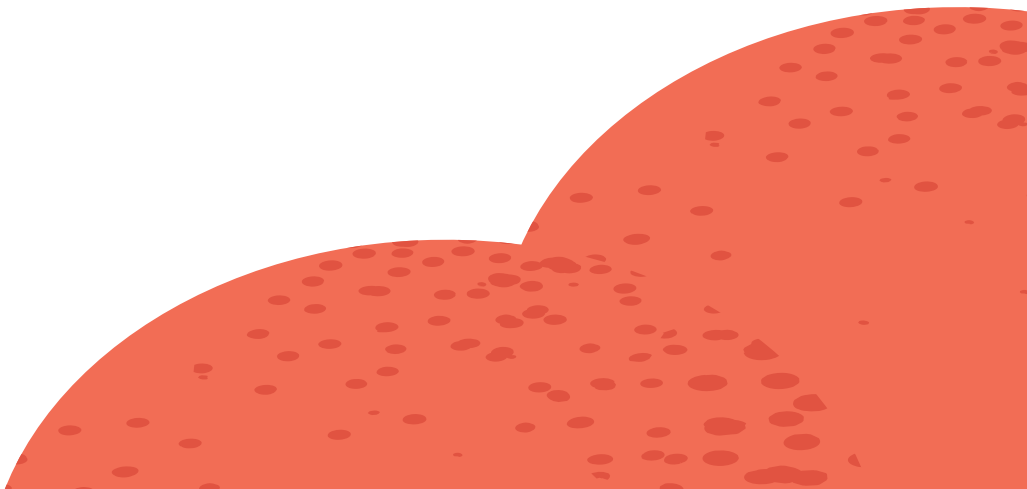
This Annual Report provides a detailed breakdown of all the key data covering the work of the Patient Advocacy service in 2021. The report describes the issues advocates encountered during the year, many of which were impacted by the Covid-19 pandemic.

I would like to thank those who availed of our service and the continued courage shown throughout this unprecedented time. I would like to thank the Department of Health for their ongoing guidance and support of the Patient Advocacy Service. I would also like to express my gratitude to all the staff of the Patient Advocacy Service for their dedication and commitment in providing professional independent advocacy services throughout 2021 and to the Board of the National Advocacy Service for People with Disabilities for their continued support and guidance.

Covid-19 continued to have a negative impact on the lives of people across Ireland in 2021, including the people the Patient Advocacy Service support and, while the situation has improved significantly for many in 2022, the Service remains committed to providing the highest level of advocacy to people who need us. We also must continue to remember those people who lost their lives, that the challenges the HSE and health services continue to deal with are recognised, and that we continue to learn from the mistakes that were made.

Louise Loughlin,

National Manager of the National Advocacy Service for People with Disabilities (NAS), which delivers the Patient Advocacy Service



1. Patient Advocacy Service Highlights



1,054 of the enquiries were short-term, such as providing people with information by phone and referrals to other support services.



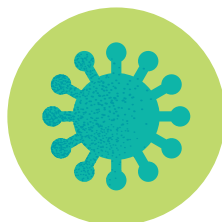
151 of the enquiries were given full 1-1 advocacy support, including supporting people with written correspondence and attending meetings with them.



The Patient Advocacy Service carried out **586** promotions in 2021, including presentations and offers of leaflets and posters.



The Patient Advocacy Service website was visited by over **12,100** new users in 2021.



313 of the people supported by the Patient Advocacy Service had issues impacted by Covid-19.



The Patient Advocacy Service closed **1,153** contacts in 2021. **49** of those were carried forward from 2020, the rest were opened and closed in 2021.

Some of the biggest complaint issues for people in public acute hospitals worked on by the Patient Advocacy Service's advocates were visiting being unavailable, difficulty phoning healthcare units, and staff not communicating care plans.



2. Our Remit

“Speaking to a patient advocate was a big help, even our chat helped me to offload my anxiety.”

Patrick, who was supported by the Patient Advocacy Service in 2021



2.1 Patient Advocacy Service Remit

The Patient Advocacy Service is commissioned and funded by the **National Patient Safety Office** in the **Department of Health (DoH)**. The Patient Advocacy Service is fully independent of the HSE.

The Patient Advocacy Service is provided under the auspices of the National Advocacy Service for People with Disabilities (NAS). NAS, which is funded and supported by the Citizens Information Board (CIB), provides an independent, confidential and free, issues-based representative advocacy service to people with disabilities.

The Patient Advocacy Service provides free, independent and confidential information and support to people who want to make a formal complaint through the HSE 'Your Service, Your Say' complaints process in relation to the care they have experienced in a public acute hospital or HSE-operated nursing home, and in the aftermath of a patient safety incident.

The Patient Advocacy Service empowers people by supporting them to assert their views and seek answers and outcomes through the HSE complaints process. The advocates do not take sides on an issue, but rather seek to ensure that a process is fair, and that the individual's views, concerns, and decisions are addressed. The Patient Advocacy Service also aims to work with hospital teams to improve complaints systems.

In May 2021, the Patient Advocacy Service expanded its remit to provide advocacy to residents of HSE-operated Nursing Homes. The Service is now also providing advocacy services to:

- ▶ Users of HSE Funded Nursing Homes.
- ▶ Users of nursing homes operated under arrangement pursuant to S.38 of the Health Act 2004.

The service supports those who wish to make a complaint through the HSE 'Your Service, Your Say' complaints process about the care they have received in their Nursing Home.



Case Study

Angela's Story: Issues Regarding Hospital Care

My name is Angela and I contacted the Patient Advocacy Service because I had concerns around the care provided to my mum who passed away in hospital during the Covid-19 pandemic. I wanted to access my mum's records and to make a complaint about the poor level of care she had received.

My mum had been admitted to hospital, but I was not allowed to visit her due to the Covid restrictions. A decision was made to discharge her, but I was not contacted by patient services and there was no discharge plan in place.

My mum's condition worsened, and she was readmitted to hospital. In the days that followed I tried to contact the hospital to find out what was going on, but my calls were not returned. Late one evening, I was contacted by the hospital to inform me that mum was seriously ill. However, when we arrived at the hospital, she had passed away.

The advocate I spoke to in the Patient Advocacy Service explained the HSE's Freedom of Information policy and supported me to write a letter to the hospital requesting my mother's records. Once I received the records, the advocate helped me to review them.

With the advocate's support, I submitted a letter of complaint to the HSE, requesting a clinical review of my mum's care and a meeting. However, my request was not granted, and I felt the complaint response did not fully deal with my issues.

My advocate supported me to pursue the complaint by requesting an internal HSE review. As a result, the hospital offered a meeting where I was given an apology and recommendations for improvement were initiated. I am satisfied that my concerns have been listened to.



3. Our Service

“My advocate supported me to feel enabled, empowered and in control.”

Claire, who received support from an advocate during 2021



3.1 Responding to Covid-19's Ongoing Impact

Covid-19 restrictions and disruptions continued to have a significant impact on the services provided by the **Patient Advocacy Service** in 2021, particularly during the periods of lockdown in the first half of the year.

It often proved difficult for the Service's advocates to progress complaints and gain access to Freedom of Information requests. Meetings were regularly postponed, leaving families waiting for months to discuss review findings or complaint issues.

Despite these challenges, the Patient Advocacy Service continued to deliver high quality advocacy in 2021. The Service's staff worked effectively from

home, with blended working introduced where possible. The Service continued to offer people support through its national phone line and online methods of enquiry (email, website) and it further embraced innovative ways of working such as video calls, emailing and text messaging.

The Service's advocates regularly reached out to acute public hospitals to seek updates on how they were progressing complaints received and Freedom of Information requests. The Service also provided valuable links for people who have had difficulty in accessing information from their care settings.

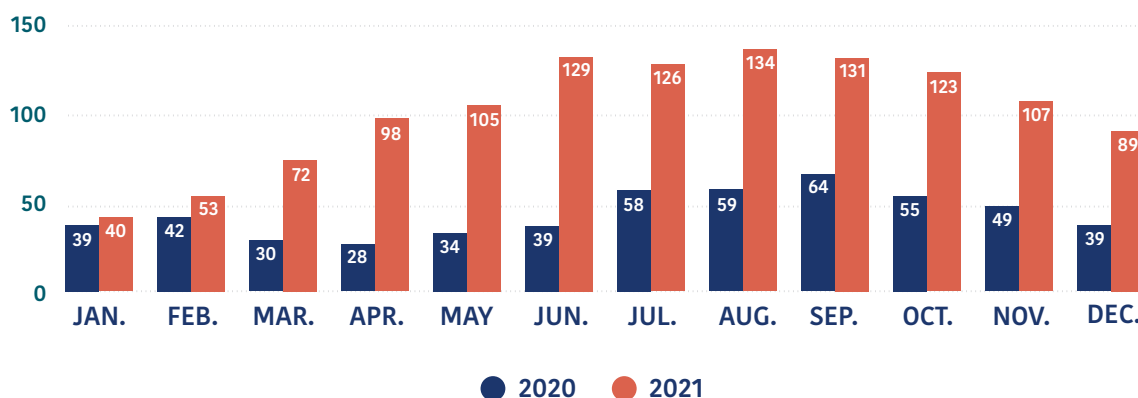
3.2 Our Work in 2021

"Thank-you for being empathic and patient."

James, who was supported by the Patient Advocacy Service in 2021

The Patient Advocacy Service works to ensure a high-quality advocacy service is provided to people who need our support, with professionally trained advocates focused on continuous development. The Patient Advocacy Service is fully aligned with the NAS Code of Practice and suite of policies. The Patient Advocacy Service's goal is to continue to improve the advocacy it provides. To achieve this, its advocates take part in weekly team meetings, practice development, and ongoing case review and monitoring.

2021 was the second full year of service delivery for the Patient Advocacy Service. In 2021, the Service received 1,205 new complaint enquiries, of which 3,382 separate complaint issues were identified. This was an increase of 125% on 2020 when we received 535 complaint enquiries. The table below shows the numbers of new contacts by month in 2021, compared with 2020.



Despite the ongoing impact of Covid-19, the number of new contacts to the Service continued to increase throughout 2021. This was due to the running of a regional advertising campaign from April – July 2021 to raise awareness of the Service among the public across Ireland. The campaign significantly increased the number of new contacts to the Service.

Of the 1,205 new contacts received by the Service, 1,054 were short term advocacy enquiries, including one-off representations, such as sending a person a template letter, providing information by phone, and signposting and referrals to other support services.

151 new contacts were given full 1-1 advocacy support. This work involved supporting people to write correspondence, attending meetings with the person in a supportive capacity, and supporting them to have their concerns heard.

313 of the people supported by the Patient Advocacy Service in 2021 had issues impacted by Covid-19. This is a much higher number than in 2020 when 154 of the individuals supported had issues impacted by Covid-19.

In 2021, the Patient Advocacy Service expanded its remit to provide advocacy to residents of HSE-operated Nursing Homes. This expansion took place in May 2021 which meant there was limited time to promote the Service's new remit to nursing home residents and their families. However, we received 36 new complaint enquiries in relation to HSE-operated nursing homes.

Launch of 'Advocacy matters: Impact of Covid-19' Reports

The Patient Advocacy Service worked jointly with NAS to launch a series of 'Advocacy Matters: Impact of Covid-19' reports in autumn/winter 2021.

The reports focussed on the work carried out by both Services during the Covid-19 pandemic, particularly during the period from March 2020 - March 2021, outlining the support they provided and the positive outcomes this advocacy support helped to achieve.

The aim of the reports was to show the hugely detrimental impact the Covid-19 pandemic, its restrictions, and the subsequent disruptions to healthcare services in Ireland have had on the people we support.

They also conveyed the key role that advocacy plays in supporting people who may be vulnerable in Irish society, particularly during periods of crisis.

Four reports were developed, with 2 of the reports focused specifically on the work of the Patient Advocacy Service. These were:

- ▶ Report 3: **Advocating for People Regarding Health & Social Care during the Covid-19 Pandemic**
- ▶ Report 4: **Advocating for People Living in Nursing Homes during the Covid-19 Pandemic**

The reports make it clear that there is a need to ensure that the voice and human rights of people are always recognised. Given the ongoing impact of the Covid-19 virus, they stress the need for health and social care services to learn from people's negative experiences, using their feedback to continue to improve their service delivery.

The Patient Advocacy Service and NAS organised two online webinars (the first in October and the second in December) to launch the 'Advocacy Matters' reports. Over 270 people, from 120+ separate organisations, attended the two events. These included representatives from the Department of Health, the Health Service Executive (HSE), CIB (Citizens Information Board), HIQA (Health Information and Quality Authority), government departments, advocacy and community organisations and political representatives.

An aspect of the webinars that proved particularly engaging for those in attendance was the use of videos featuring audio interviews with people who have been supported by the Patient Advocacy Service telling their own stories. Feedback from attendees was that these videos were very powerful and emotional, and helped to convey the human side of our work.

Both launch events received significant national print media coverage, including 2 articles on the RTE News website (**first event/second event**), 2 articles in the **Irish Examiner** and an article in the **Irish Times**. NAS National Manager, Louise Loughlin, was also interviewed on Cork's C103, Limerick's Wired FM, Clare FM, and Kildare FM.



Patient Advocacy Service Work¹

Year	Patient Advocacy Service Cases
2019	65
2020	535
2021	1,205

3.3 Complexity of Work by Our Service

The **Patient Advocacy Service** uses the Healthcare Complaints Analysis Tool (HCAT)², developed by the London School of Economics and Political Science, to categorise all the complaint issues that are presented. The HCAT was developed as a framework to gather information on healthcare complaints so this information can be used to improve service delivery.

The Patient Advocacy Service used HCAT to record the complaint issues for the 1,205 advocacy contacts in 2021. Of these contacts, 338 were outside the remit of the Service.

There were 653 contacts that had between 1 and 5 complaint issues, 151

contacts that had between 6 and 10 complaint issues, and 27 contacts that had between 11 and 15 complaint issues. There were also a further 9 contacts with 16-27 complaint issues.

These complaint issues included people's anxieties not being addressed, families having difficulty phoning hospital healthcare units, family visiting being unavailable in hospitals, and staff not communicating care plans to patients.

These figures show the range of issues that people in hospitals had in 2021 and how serious and complex some of their complaint issues were. Some contacts involved several different complaints at several different levels of severity.

3.4 Key Issues for Our Service

Within the Health Complaints Analysis Tool (HCAT), the complaint issues are broken down into three severity levels: level 1 (low severity), level 2 (medium severity) and level 3 (high severity).

The HCAT also lists the specific types of issues people had with their care

in relation to quality and safety, management issues (including environment and institutional processes) and relationship issues (including listening, communication and respect, and patient's rights.) The Chart below shows the top issues identified by severity rating.

¹ This table outlines the information support and empowerment advocacy casework carried out by the Patient Advocacy Service over the past three years.

² London School of Economics and Political Science's Healthcare Complaints (HCAT) Analysis Tool <https://www.hse.ie/eng/about/qavd/complaints/ysysguidance/learning-improving-and-accountability/bmjqs-2015-004596supp-new.pdf>

The complaint issues received by the Patient Advocacy Service in 2021 are broken down as follows

Severity Level	No. of Complaints Issues	Types of Complaints
Severity Level 1	822	<ul style="list-style-type: none">▶ Staff spoke in a condescending manner▶ Phone calls not returned▶ Difficult phoning healthcare unit
Severity Level 2	1,936	<ul style="list-style-type: none">▶ Anxieties acknowledged, not addressed▶ Visiting unavailable▶ Complaint not responded to▶ Rude behaviour
Severity Level 3	628	<ul style="list-style-type: none">▶ Unable to access specialist care▶ Staff ignored severe distress▶ Discharge without sufficient examination▶ Patient left with unexpected disabilities

The top 5 complaint issues in 2021 were:

1. Anxieties acknowledged, not addressed
2. Visiting unavailable
3. Difficulty phoning healthcare unit
4. Staff did not communicate care plan
5. Phone calls not returned



Case Study

Adam's Story: Complaint Regarding Appointment Cancellation

My name is Adam. I contacted the Patient Advocacy Service about a medical condition I have that was causing me a lot of pain. I require regular treatment for the condition, but I hadn't received any treatment since the middle of 2020. Several of my hospital appointments have been cancelled.

My hospital consultant said the cancellations had occurred because I was due to get my Covid-19 vaccination and the two treatments could not take place at the same time. My consultant did not seek to prioritise my vaccination and said this was the role of my GP.

I spoke to an advocate in the Patient Advocacy Service who took the time to really listen to my concerns. The advocate gave me the chance to speak openly and helped me understand the options open to me.

My advocate explained the HSE's complaint process, and the timelines involved. They advised me to contact the Risk Management Department in the hospital as the delays to my treatment were affecting my quality of life.

I contacted the department and was told an error had occurred. I was recognised as a high-risk patient requiring urgent referral for vaccination, but my name had been missed off the list. With the support of my advocate, I made a formal complaint.

Following the complaint, I received my vaccination, and my treatment was rescheduled. I am pursuing my complaint with the hospital to try and ensure this does not happen to anyone else.



4. Our Standards Work

“My advocate showed so much professional integrity in pursuing my rights.”

Adam, who used the Patient Advocacy Service in 2021



4.1 Ongoing Development of the Patient Advocacy Service

Despite the ongoing impact of the Covid-19 pandemic, in 2021 the Patient Advocacy Service took important steps forward to build its capacity and effectiveness. In February 2021, the initial term of the Patient Advocacy Service contract was extended by a period of 16 months, from June 2021 to the end of October 2022. This was followed by two key actions:

Signing of MoU between HSE and Patient Advocacy Service

In April 2021, the Patient Advocacy Service, and the Health Service Executive (HSE) signed a **Memorandum of Understanding (MoU)** pledging to work together to further improve support services for people who wish to make a complaint about the care they have received in public acute hospitals. The MoU sets out the commitment of both organisations to cooperate to ensure that people receive a timely, compassionate, and comprehensive response to their complaints.

The MoU recognises that every person has the right to make a complaint about the service they have received within HSE public acute hospitals. In the MoU, the HSE recognises the important role that independent patient advocacy can play in the complaints process, while the Patient Advocacy Service commits to helping people to improve their understanding of the HSE's complaints processes, 'Your Service Your Say' and the Incident Management Framework.

Expansion of Remit to Nursing Homes

From May 2021, the Patient Advocacy Service expanded its remit to provide advocacy to residents of HSE-operated Nursing Homes.

The Service is now also providing advocacy services to:

- ▶ Users of HSE Funded Nursing Homes.
- ▶ Users of Nursing Homes operated under arrangement pursuant to S.38 of the Health Act 2004.

The service supports those who wish to make a complaint through the HSE 'Your Service, Your Say' complaints process about the care they have received in their Nursing Home.

5. Our Policy Work

“Thanks to the advocate, I was able to make considered decisions through a difficult process.”

Michael, who received support from the Patient Advocacy Service



5.1 Stakeholder engagement

Engagement with external statutory bodies:

The Patient Advocacy Service continued to contribute to social policy in 2020 through stakeholder engagements and policy submissions. In its policy work in 2021, the Patient Advocacy Service sought to ensure that advocacy is recognised as playing an important role in ensuring that people's rights are upheld and they receive the highest level of quality care.

Throughout 2021, the Patient Advocacy Service was an active participating member of the following groups:

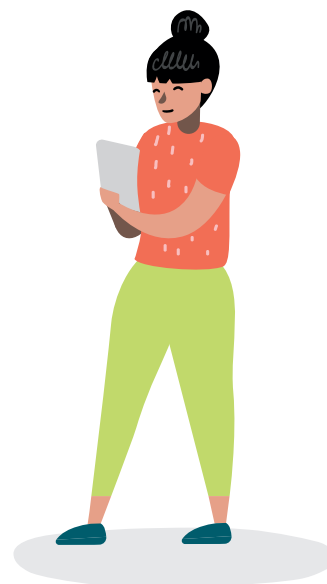
- ▶ Nursing Home Expert Report Group Implementation Reference Group
- ▶ National Care Experience Programme Steering Board
- ▶ HSE Project Group on Patient Engagement Framework
- ▶ National Inpatient Experience Survey Programme Board
- ▶ Department of Health Nursing Home Report Reference Group membership
- ▶ Steering Committee on the Post-Partum Haemorrhage Quality Improvement Initiative (NPEC)

5.2 Public Consultations and Submissions

The Patient Advocacy Service responded to public consultations and policy submissions in areas related to its remit.

These included:

- ▶ Interim Regulatory Reform in Nursing Homes - September 2021
- ▶ Serious Patient Safety Incident Bill - September 2021
- ▶ Stakeholder consultation on implementation of health and social care standards
- ▶ HIQA Corporate Plan feedback - November 2021
- ▶ HSE Open Disclosure Policy Revision



6. Promoting Our Service

“The support I received from my advocate had a big impact on my quality of life.”

Joanne, who was supported by an advocate from the Patient Advocacy Service in 2021



The Covid-19 pandemic and the subsequent restrictions continued to have a significant impact on outreach and promotional work carried out by the Patient Advocacy Service in 2021. Covid restrictions meant that public gatherings and face-to-face meetings still could not be held. Despite these issues, the Patient Advocacy Service continued to proactively promote its Service in 2021.

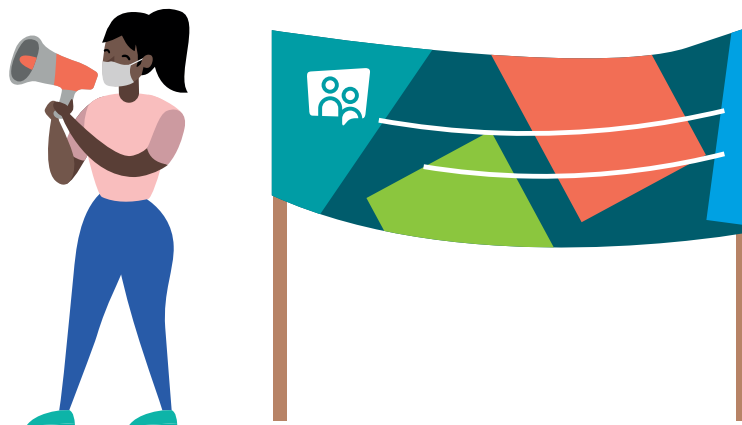
6.1 Promotional Work

A key element of this promotional work was a regional advertising campaign which ran from April 2021 – July 2021. The campaign involved radio and print adverts that targeted local media in all 26 counties in Ireland. The aim was to ensure as many people as possible across Ireland, including those considered hardest to reach, were aware of the Service and the support it provides. The regional ad campaign led to a 125% increase in the number of new cases received by the Service.

The Service also increased its use of social media in 2021. In support of the advertising campaign, a social media marketing campaign was run on Facebook and Google Ads:

- ▶ The Service's Facebook page, regarded as the key platform for engaging the public, increased by 20%, from around 2,100 followers at the start of 2021 to over 2,500 at the end of 2021.
- ▶ The use of a Google Ad to promote the Service proved particularly effective. The Google Ad was promoted from the start of April 2021 to the end of the year. It was clicked on nearly 4,400 times and led to 456 direct calls to the Service.

As a result of increased interaction and engagement across our social media platforms, visitors to the Patient Advocacy Service gradually increased over the course of the year. The website had 12,213 users in 2021, of which 12,144 were new users. This was nearly twice the number of new visitors to the website that we received in 2020.





INFORMATION | SUPPORT | EMPOWERMENT

The Patient Advocacy Service is funded and supported by the Department of Health (DoH)



The Patient Advocacy Service is delivered by the National Advocacy Service for People with Disabilities (NAS).

Patient Advocacy Service

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