# Patient Advocacy Service Annual Report 2022

## Contents

### Foreword by the Chairperson

### Patient Advocacy Service Highlights 2022

### Patient Advocacy Service Remit

### Our Service

### Patient Advocacy Service Work in 2022

### Launch of First-Ever Casebook

### Complexity of Work by Our Service

### Key issues for Our Service

### Financial Overview

### Our Standards Work

### Ongoing Development of the Patient Advocacy Service

### Our Policy Work

### Stakeholder Engagement

### Public Consultations and Submissions

### Promoting Our Service

### Foreword by Chairperson

Welcome to the 2022 Annual Report for the National Advocacy Service for People with Disabilities (NAS) and the Patient Advocacy Service. 2022 was a challenging year with significant changes both for our services and wider society. It was the 3rd year of the Covid-19 pandemic. The issues associated with the pandemic, its restrictions and its disruptions to health services across the country continued to disproportionately impact people that access both our services.

2022 again demonstrated the significant need for our services. NAS continue to operate under significant pressure and there was a large demand across the country for our services. In the past year, our waiting list has grown from 161 to 250. Despite this, our Service has not received funding for any new permanent posts since 2011.

The Patient Advocacy Service saw an increase of 54% in service enquiries in 2022, in response to this and in line with our contractual obligations we have continued to build capacity and effectiveness in 2022. We have also grown the service by opening offices in Galway and Cork and expanded our remit to provide support for residents of nursing homes.

This period also saw a dramatic reduction in Covid-19 cases and the lifting of almost all restrictions. While these were immediate changes for many in society, the shift back to “normal” life was slower for a lot of the people who access our services, and the residual impact will require significant management for some time to come.

Alongside this, NAS Advocates worked on a wide range of other issues during 2022. We continued to see people contacting our services with issues related to housing, residential and healthcare settings and decision-making. I note that issues like these are directly linked to someone’s ability to live a meaningful and full life within their communities. The interactions between advocates and people that access our services are vital as they underline to the person the importance of their human rights.

Communication was a significant theme reported by Advocates working in the Patient Advocacy Service in 2022. People seeking advocacy reported problems such as people’s anxieties not being addressed, lack of capacity for visiting, poorly communicated healthcare plans, people having difficulty phoning healthcare units and staff speaking to people in a condescending manner. These are important issues and have detrimental effects on people’s lives when they are not addressed.

It is the experience of our Advocates that people who seek advocacy support do so because they have exhausted all other options. In 2022, our Advocates worked tirelessly to ensure that the voices of people with disabilities were heard, will and preferences were upheld, and that people’s voices are protected and listened to.

This Annual Report is broken into two sections. Section one provides detailed information on all the work of the NAS service in 2022. Section two details similar information related to the Patient Advocacy Service.

Both Sections highlight key data around the number of enquiries received by our services, the number of cases worked on by our Advocates and the complexity of the cases we worked on. This document illustrates the wide range of people that we work with and the types of issues they face. It provides an insight into how NAS Advocates work with people through several case examples. I wish to express my sincere thanks to the Citizens Information Board for their continued championing of NAS and their ongoing support and assistance of our work. I would also like to thank the Department of Health for their ongoing guidance and support of the Patient Advocacy Service. In addition, I would like to express the Board’s gratitude to all the staff of NAS and the Patient Advocacy Service for their dedication and commitment to providing professional advocacy services throughout 2022.

Rosemary Smyth, Chairperson of NAS Board

### Patient Advocacy Service Highlights 2022

The Patient Advocacy Service provided support to people in 2022, covering 6,101 separate complaint issues.

This was an increase of 54% on 2021 when we received 1,205 complaint enquiries.

1,698 of the enquiries were short-term, such as providing people with information, advice, assistance, and signposting or referring to other support services.

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

The Patient Advocacy Service provided support to 1,346 people who wanted to complain about their care in public acute hospitals.

The Service also provided support to 62 people who wanted to complain about their care in nursing homes.

The Patient Advocacy Service carried out 304 promotions in 2022, including presentations and offers of leaflets and posters.

The Patient Advocacy Service closed 1,604 contacts in 2022. 124 of those were carried forward from 2021, the rest were opened in 2022 and closed in 2022.

Some of the biggest complaint issues for people in public acute hospitals worked on by the Patient Advocacy Service’s advocates were anxieties being acknowledged but not addressed, visiting being unavailable, questions being acknowledged but not responded to, staff not communicating care plans, and staff speaking in a condescending manner.

### 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 relevant complaints process in relation to the care they have experienced in a public acute hospital, or nursing home, and in the aftermath of a patient safety incident. For public acute hospitals and HSE-operated nursing homes, people can make complaints through the HSE’s Your Service Your Say complaints process, and for private nursing homes, people can make complaints through each nursing home’s own complaints process. The Patient Advocacy Service empowers people by supporting them to assert their views and seek answers and outcomes through the relevant 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 desired outcomes are addressed. The Patient Advocacy Service also aims to work with hospital teams to improve complaints systems.

In 2022, the growth of the Service continued. In May 2022, following a competitive tendering process, NAS was awarded the contract to operate the Patient Advocacy Service for a further five years by the National Patient Safety Office in the Department of Health (DoH). The contract will run from October 2022 until October 2027.

As part of the contract, the Patient Advocacy Service announced in October 2022 that it was further expanding its remit to provide support for residents of private nursing homes and their families.

### Case Study

#### Clodagh’s Story: Issue’s Regarding Hospital Care

My name is Clodagh. I experienced some issues while giving birth in a maternity hospital and I was discharged into the community midwives’ care. I started to experience severe pain, but I felt the issue was ignored.

I was referred to A&E where I was left waiting for hours before being examined and told to go home. I refused to leave and requested my blood test results, which indicated an infection. I was referred to a general hospital for a CT scan, as this service was not available at my maternity hospital. In the end, I was admitted back into the maternity hospital for several days.

I was angry at having to wait for such a long time in A&E. I also felt I received poor care and experienced poor communication. I was almost given incorrect medication. A few weeks later, I met with a consultant in the maternity hospital for a medical review and I received no proper information and felt like I was being dismissed when I expressed my point of view.

I contacted the Patient Advocacy Service and spoke to an Advocate who listened to my story and provided information and guidance on the different stages of the HSE complaints process, Your Service Your Say. The Advocate reviewed my medical files and helped me to research the hospital policies that were relevant to my experiences.

My Advocate supported me to write letters of complaint to both the general hospital and the maternity hospital. The Advocate helped me to outline what my issues were and the outcomes I wanted to achieve. As a result of the letters I sent, the general hospital offered to meet with me.

My Advocate helped me to prepare for the meeting and attended it with me. This was a big help, and I was very happy with how things went. There were senior hospital staff in attendance, and I felt I was listened to. The hospital said it would learn from the mistakes it had made and agreed to implement a series of recommendations to ensure they were not repeated.

When it came to the response from the maternity hospital, I was not as happy with the result. However, one positive was the plan to improve the process of referring patients between the two hospitals.

Overall, I am happy with the outcomes achieved following my complaints and I am grateful for the support of my Advocate.

### Our Service

#### Our Work in 2022

“I would not have been able to go through this process without your advice.”- Kate, who was supported by the Patient Advocacy Service in 2022

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 an Organisational Code of Practice and suite of policies. The Service’s goal is to continue to improve. To achieve this, advocates take part in weekly team meetings, practice development, and ongoing case review and monitoring.

2022 was the third full year of service delivery for the Patient Advocacy Service. The Service received 1,859 new enquiries, of which 6,101 separate complaint issues were identified. This was an increase of 54% on 2021 when we received 1,205 enquiries.

The number of new contacts to the Service continued to increase throughout 2022. This was due to the running of two national advertising campaigns to raise awareness of the Service among the public across Ireland. The first campaign ran for 5 weeks in January and February 2022 and targeted national print and radio media, while the second campaign ran for 6 weeks in October and November 2022 and solely targeted national radio. These campaigns significantly increased the number of new contacts to the Service.

Of the 1,859 new contacts received by the Service, 1,698 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.

161 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.

The Patient Advocacy Service provided support to 1,859 people, 1,346 of whom wanted to make complaints about their care in public acute hospitals. The Service also provided support to 38 people who wanted to make complaints about their care in HSE-operated nursing homes.

219 of the people supported by the Patient Advocacy Service in 2022 had issues impacted by Covid-19. This was lower than in 2021 when 313 people had issues impacted by Covid-19.

Following the expansion of the Service’s remit in October 2022 to provide advocacy support to residents of private nursing homes and their families, we received 24 new complaint enquiries in relation to private nursing homes.

Year Patient Advocacy Service Cases

2019 65

2020 535

2021 1205

2022 1859

### Launch of First-Ever Casebook

The Patient Advocacy Service joined the National Advocacy Service for People with Disabilities (NAS) to launch our first-ever Casebook in December 2022.

The Casebook contains a selection of the many advocacy cases worked on by both of our Services over the past couple of years, including during the Covid-19 pandemic. It is a source of information for anyone who wants to find out more about our work and its impact.

The Casebook provides an insight into how independent, professional advocacy can positively impact on people’s lives and protect their human rights. It illustrates the diverse range of people who access advocacy services in Ireland and the many issues covered by both NAS and the Patient Advocacy Service.

The case examples in the publication demonstrate how our Services help breach gaps in systems, ensure best practice across public services and promote positive systemic changes. They show how our advocacy work has a positive impact both for individuals and in communities across Ireland.

### Complexity of Work by Our Service

The Patient Advocacy Service uses the Healthcare Complaints Analysis Tool (HCAT)3, developed by the London School of Economics and Political Science, to categorise all the complaints 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 6,101 complaint issues for the 1,859 advocacy contacts in 2022. Of these contacts, 487 were outside the remit of the Service.

There were 901 contacts that had between 1 and 5 complaint issues, 285 contacts that had between 6 and 10 complaint issues, and 78 contacts that had between 11 and 15 complaint issues. There were also a further 25 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 2022 and how serious and complex some of their complaint issues were. Some contacts involved several different complaints at several different levels of severity.

### Key Issues for Our Service

As outlined earlier, the Patient Advocacy Service identifies issues within individual contacts in line with the London School of Economics and Political Science’s Health Complaints Analysis Tool (HCAT).

Within the 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 complaint issues received by the Patient Advocacy Service in 2022 are broken down as follows:

Severity Level No. of Complaints/Issues Types of Complaints

Severity 1 3426 Question acknowledged not responded to

Staff spoke in condescending manner.

Patient monitoring delayed.

Patient not involved in care plan.

Severity 2 1529 Anxieties acknowledged, not addressed.

Visiting unavailable.

Staff did not communicate care plan.

Patient not monitored properly.

Complaint not responded to.

Severity 3 1146 Unable to access specialist care.

Staff ignored severe distress.

Discharge without sufficient examination.

Patient left with unexpected disabilities.

The top 5 complaint issues in 2022 were:

1. Anxieties acknowledged, not addressed.

2. Visiting unavailable.

3. Question acknowledged not responded to.

4. Staff did not communicate care plan.

5. Staff spoke in condescending manner.

### Financial Overview

The National Advocacy Service for People with Disabilities (NAS) is fully funded by the Citizens Information Board. NAS also hosts the Patient Advocacy Service which is funded by the Department of Health.

The Citizen Information Board budget allocation for NAS in 2022 was €2,973,054. This generated an underspend of €190,242 which was returned to CIB in 2023. CIB advised in September 2022 the budget was to be re-profiled. This resulted in a reduction in the budget of €131,853 for NAS for 2022.The reason for the underspend in NAS funding is due to restrictions associated with how funding can be utilised and difficulties associated with predicting staffing levels and associated costs on an annual basis. The budget allocation provided for 48 FTE positions across the country. This level of funding has not changed in over ten years, despite a substantial increase in demand for the NAS service which has led to ongoing increases in enquiries to the service and a growth in our waiting list.

The Patient Advocacy Service received €1,291,811 from the Department of Health in 2022. This funding was used to provide for 18 FTE positions across the country to support delivery of the advocacy service to people seeking to make a complaint about an experience they had in a Public Acute Hospital or Nursing Home and also providing support after a patient safety incident.

### Case Study

#### James’ Story: Complaint Regarding Accommodation in Nursing Home

My name is James, I am in my mid-sixties, and I am a resident in a HSE operated nursing home. I contacted the Patient Advocacy Service because I was concerned about the actions of another resident in the home.

I was sharing a room with three other residents. I liked the room and enjoyed the company of the people, except for one person, who I felt was loud and disruptive. I decided I wanted to make a complaint.

I contacted the Patient Advocacy Service and spoke to an Advocate who helped me clarify the details of the case, gather information about the issues and any other facts I wanted to raise, and work out what I wanted to achieve.

My Advocate also gave me advice around my safeguarding rights and the HSE policies. With my consent, the Advocate spoke to the Assistant Director of Nursing in the home on my behalf.

I made a formal complaint and had a meeting with the Person in Charge of the nursing home and the Assistant Director of Nursing. As a result of making the complaint, I was offered a bed in another communal room or a room of my own. However, I decided I did not want to leave the room.

The Assistant Director of Nursing said the nursing home would provide extra carer hours for the room and would make a carer available to support me if I wanted to leave the room or have a break. I was happy with the outcome and the support of my advocate.

### Our Standards Work

“You are the only one who believed me, understood and listened with compassion.”- Patrick, who used the Patient Advocacy Service in 2022

#### Ongoing Development of the Patient Advocacy Service

In 2022, the Patient Advocacy Service took important steps forward to build its capacity and effectiveness. This involved three important steps:

#### NAS Awarded Contract to Deliver Service for Further Five Years

Following a competitive tendering process, the National Patient Safety Office in the Department of Health (DoH) awarded the contract for the Patient Advocacy Service to the National Advocacy Service for People with Disabilities (NAS) for a further five years. The new contract will run from October 2022 until October 2027. NAS was delighted to have been awarded the contract, which will mean it can continue to provide professional, high-quality advocacy support for people across Ireland.

Welcoming the new contract, Minister for Health, Stephen Donnelly TD, said:

“I am delighted to welcome the commencement today of a new contract of service for the Patient Advocacy Service, which will cover the period 2022 - 2027. The Patient Advocacy Service provides a vital service to patients and their families to facilitate complaints when they are not happy with the care they have received. Public feedback about the Patient Advocacy Service has been extremely positive and I look forward to the continued provision and expansion of the service in the years ahead.”

#### Expansion of Remit to Private Nursing Homes

From May 2021, the Patient Advocacy Service expanded its remit to provide advocacy support to residents of HSE-operated nursing homes. In 2022, the expansion of the Service continued. From 1st November 2022, the Patient Advocacy Service announced that it will also be providing this advocacy support to residents of private nursing homes.

In order to provide an appropriate quality service, the Patient Advocacy Service required a right to access private nursing homes. The Department of Health (DoH) made changes to the regulations outlined in the Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People), which gave greater recognition to the role of independent advocacy services.

This was a very significant step in embedding advocacy services within private nursing homes and providing a legislative basis for advocacy.

Minister for Mental Health and Older People, Mary Butler said:

“The extension of the Patient Advocacy Service to private nursing homes is a significant and positive initiative. It is extremely important that this service is available to all those in Nursing Home Care. The service will provide private nursing home residents with expert support and guidance if they need it and more broadly seeks to place greater emphasis on the voice and choice of residents, empowering them to shape and improve their care. This was a key recommendation of the Expert Panel Report for Nursing Homes during Covid-19 and the roll out was a priority of mine.”

#### Opening of New Offices in Galway and Cork

To provide for the successful delivery of our national service delivery model and maximising the Service’s opportunity for quality service provision and growth, a Galway hub office was identified and became operational in April 2022 with space for 3 staff. A premises in Cork for 8 staff was identified and will become operational in early 2023.

### Our Policy Work

“My Advocate was empathetic, courteous, a great listener and very professional.”- Eve, who was supported by an advocate from the Patient Advocacy Service in 2022

#### Stakeholder engagement

Engagement with external statutory bodies

The Patient Advocacy Service continued to contribute to social policy in 2022 through stakeholder engagements and policy submissions. In its policy work in 2022, 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 2022, the Patient Advocacy Service was an active participating member of the following groups:

• Health and Social Care Expert Working Group for Prescribed Classes of Professionals – Assisted Decision Making (Capacity) Act 2015.

• National Care Experience Programme Steering Group.

• HSE Project Group on Patient Engagement Framework.

• Steering Committee on the Post-Partum Haemorrhage Quality Improvement Initiative (NPEC).

• National Maternity Clinical Guidelines Expert Working Group.

• National Open Disclosure Measurement Project Group – Workstream 3: Measurement of Patient Experience in Relation to Open Disclosure.

• HIQA Working Group on Development of National Nursing Home Experience Survey.

• HIQA Working Group on Development of E-Learning: Fundamentals of Advocacy.

• Mater Hospital ADM Implementation Group.

#### Public Consultations and Submissions

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

These included:

• Decision Support Service Consultation on Codes of Practice.

• Medical Council Research Strategy Survey.

• Government Reform Unit focus group on review of Freedom of Information Act.

• Dept of Health Policy & Governance Unit Regarding development of Complaints & Patient Safety Policy Incident Framework.

• Crowe Research for Independent Patient Safety Council Regarding Culture & Principles Underpinning the Management of PSIs.

• National Care Experience Programme Regarding National Maternity Bereavement Survey.

• Medical Council Draft Standards for Medical Education and Training.

• The Mental Health Commission Strategic Plan.

• Public consultation on the Open Disclosure Framework.

• National Screening Service Regarding Patient Cervical Screening Reviews.

Case Study

#### Sarah’s Story: Complaint Regarding Hospital Care and Communication

My name is Sarah. My husband Liam became very ill one day and was brought by ambulance to the local public acute hospital.

Liam was in the hospital for several weeks and was moved into palliative care. Despite the lifting of general Covid-19 measures, restrictions were still in place in the hospital, and I was not allowed to visit my husband at certain times. Liam passed away in the hospital before he could be moved to hospice care.

I contacted the Patient Advocacy Service because I was unhappy with the care and treatment Liam had received. My concerns included issues about the pain medication that was administered, poor communication and information from clinical staff, and a lack of empathy and kindness from some nursing staff.

I spoke to an Advocate from the Service who explained the options available to me when it came to making a complaint. My Advocate outlined the HSE’s complaints process and helped me to get copies of my husband’s medical files from the hospital. The Advocate supported me to understand the files and helped me to send a complaint letter to the hospital, explaining my concerns and outlining the questions I wanted to be answered. However, months passed, and I did not receive any response to my complaint.

My Advocate explained the options available to me and empowered me to escalate the issue to the hospital group. As a result, I received a response to my complaint, but I was not happy with some of the answers provided.

A meeting was offered by the hospital to discuss the complaint and response further. I was supported by my Advocate to prepare further questions for the meeting, and she came with me to provide support.

This time I was much happier with the result. The hospital presented an action plan to improve care for patients in similar situations, including better support for families and educational sessions on palliative care to be given to staff. I was also offered bereavement counselling and given the opportunity to take part in feedback and learning sessions that were being organised for hospital staff.

### Promoting Our Service

“What a wonderful service, I’m so glad I heard your advert on the radio.”- Jamie, who was supported by an advocate from the Patient Advocacy Service in 2022

The Patient Advocacy Service continued to proactively promote its Services in 2022. We carried out a range of advertising and promotional activities during the year which played a significant role in further increasing awareness and understanding of the Service. As a result, new contacts to the Service increased by 54%, from 1,205 in 2021 to 1,859 in 2022.

A key element of this work were two national advertising campaigns.

The first advertising campaign ran for 5 weeks across January and February 2022. This was a short-term campaign aimed at further raising awareness of the Service at national level. A radio advertisement was played on RTE Radio 1 and Today FM, and a print advertisement appeared in the Sunday Independent and Sunday World. The campaign resulted in 185 new contacts to the Service in January alone, while 20 new cases were created in the month. This campaign helped the Service to understand that far more people were contacting it as a result of hearing our radio adverts than viewing our print adverts.

The second advertising campaign, which focused solely on radio advertising, ran in October and November 2022. The Service ran radio advertisements on Ireland’s three biggest radio stations: RTE Radio 1, Today FM and Newstalk. The adverts ran for 6 weeks, ensuring sustained promotion over a prolonged period. The impact of the campaign was immediate. The Patient Advocacy Service received 238 new contacts in November alone, the highest number of new contacts the Service has ever achieved in a single month.

Also key to the Service’s promotional activities were the promotional meetings senior staff from the Patient Advocacy Service had with senior management teams from public acute hospitals across Ireland.

The Service’s staff raised awareness of the Service and discussed how the Patient Advocacy Service and hospitals can share learning, highlight systemic issues, and work together to improve the patient experience. Information about the Patient Advocacy Service has been included on hospital websites, e-zines and displays.

The Patient Advocacy Service also continued to increase its use of social media in 2022. 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 12%, from around 2,500 followers at the start of 2022 to over 2,818 at the end of 2022.

• The use of a Google Ad to promote the Service continued to prove particularly effective. The Google Ad, which was run throughout the year, was clicked on nearly 8,500 times, and led to 416 direct calls to the Service.

As a result of increased interaction and engagement across our social media platforms, visitors to the Patient Advocacy Service website increased significantly over the course of the year. The website had 22,119 users in 2022, of which 22,013 were new users. This was nearly twice the number of new visitors to the website that it received in 2021.

#### Events and Conferences

With the lifting of Covid-19 restrictions in 2022, it was possible for staff members to attend many more in-person public events during 2022, with the aim of meeting key stakeholders and the wider public. These included: Senior Times LIVE events (in Dublin in April and Cork in November), the Future Health Summit (May 2022 in Dublin), the Cork Summer Show (June 2022) and The National Ploughing Championships (held in Co. Laois in September 2022).

The Patient Advocacy Service also attended the National Patient Safety Conference in Dublin Castle. A team for the Service joined over 500 health delegates from across the healthcare sector for the conference, which was the first to be held in person since the Covid-19 pandemic began. As well as presenting at the conference, the Service’s staff had the opportunity to speak to Minister for Health, Stephen Donnelly, about the development of the service, advocacy, communication and engagement.