Supporting families affected by primary and secondary immunodeficiency

Misunderstood and underserved

2023 patient experience survey of Primary and Secondary Immunodeficiency Disorders (PID & SID) services

August 2025

C-ANPROM/GB/IG/0542 – August 2025

This project has been developed in collaboration between Immunodeficiency UK and Takeda UK Limited. Both Immunodeficiency UK and Takeda UK Limited have provided input into the development and roll-out of the survey, and contributed editorial review of the summary report. Takeda UK Limited contributed financial support.

About Immunodeficiency UK

Immunodeficiency UK was registered as a charity on 20 January 2021 as a continuum of the work of Primary Immunodeficiency UK (PID UK) in representing and supporting individuals and families affected by primary immunodeficiency in the UK. From 2013 to the launch of Immunodeficiency UK, PID UK operated as a division of Genetic Disorders UK (company registration number 07554771 and registered charity number 1141583).

The charity officially launched on 1 April 2021 following the transfer of all assets belonging to PID UK to Immunodeficiency UK, through a Deed of Transfer agreement approved by Board resolution from Genetic Disorders UK's trustees. Building on the work of PID UK, Immunodeficiency UK supports people affected by primary and secondary immunodeficiencies.

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About Takeda

Takeda Pharmaceutical Company Limited is headquartered in Japan and is a global, values-based, R&D-driven biopharmaceutical leader. Takeda focuses its R&D efforts on four therapeutic areas: Oncology, Rare Genetics and Haematology, Neuroscience, and Gastroenterology (GI), with expertise in immune and inflammatory diseases. We also make targeted R&D investments in Plasma-Derived Therapies and Vaccines. Our employees are committed to improving quality of life for patients.

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Foreword

In 2016, we at Immunodeficiency UK conducted our first patient experience survey to uncover perspective from those living with Primary Immunodeficiency Disorder (PID). I'm excited that Immunodeficiency UK (IDUK) can now publish the results of the latest patient experience survey in this report. Empowering patients and families to share their stories has always been one of our organisation's core missions and essential to improving service delivery and shaping effective immunoglobulin services.

The survey uncovers important points that need addressing across the patient pathway. But one figure in particular stood out to me in this survey – only half of patients say they have a good or very good quality of life post-diagnosis. It's also evident how hard it remains to receive a diagnosis in the first place.

I can't help but feel disappointed by how many people living with PID and SID continue to live with physical and mental health challenges, so many of which are avoidable. That said, the findings make IDUK as determined as ever to work with the community to push for change.

We are thankful to the patient community for giving up their time to support this crucial work; it's only made possible through the sharing of their personal experiences. We will continue our work and dedication to improving the quality of life, experiences of care and health outcomes not only for people with a diagnosis, but also those who will need support of the health service in the months and years ahead.

We look forward to working with the Government, NHS and others to urgently act upon the recommendations in this report.

Dr Susan Walsh
CEO, Immunodeficiency UK

Summary of recommendations

Following IDUK’s 2016 report, our patient experience survey conducted 7-years on suggests little progress has been made towards improving many aspects of patient experience for those living with immunodeficiencies or towards addressing its recommendations for improving care and support.

With just 52% of patients with primary and secondary immunodeficiency reporting a good or very good quality of life after diagnosis in 2023,[1] work is urgently needed to reduce variation in patients’ experiences of the care pathway and support they receive.

To achieve this:

NHS leaders, professional organisations and patient groups across the UK must work collaboratively to improve the quality of lives of patients living with primary and secondary immunodeficiency, by focusing on the following:

Symptom awareness and diagnosis

RECOMMENDATION

To enable patients to secure a timely diagnosis

- NHS leaders should work with professional organisations to promote and improve accessibility – particularly for GPs – of existing resources on **warning signs** and identify needs for additional resources, such as a digital tool, to improve symptom awareness
- NHS leaders should work with patient groups to conduct a review of patients diagnosed with PIDs in the past five years to assess the time taken and blockers to securing a diagnosis
- Professional groups should expand representation for primary care in initiatives to drive improvements in care for patients with primary immunodeficiencies (PIDs) and secondary immunodeficiencies (SIDs)

Experience of the care pathway

RECOMMENDATION

To drive improvements and reduce variation in care across the country

All primary immunodeficiency services should strive to achieve the Royal College of Physicians' Quality in Primary Immunodeficiency Services (**RCP QPIDS**) accreditation. Doing so would require them to increase focus on areas including:

- Providing regular opportunities for patient / carer feedback
- Ensuring person-centred support based on individual need
- Monitoring and reporting on quality metrics
- Ensuring appropriate facilities and equipment are made available and information and training provided for home therapy

All services should adhere to standards set out in the UK Primary Immunodeficiency Network (UK-PIN) and the British Society of Immunology (BSI) **consensus statement,**[2] including:

- All patients should be able to choose how their immunoglobulin treatment is administered and to have treatment at home, where clinically appropriate
- Patients with PID who are established on immunoglobulin replacement therapy (IgRT) and have no complications should be monitored at an immunology specialist clinic at least every six months

National policymakers should work with the patient community to develop an assessment in relation to patient quality of life for local services to complete on an annual basis.

RECOMMENDATION

To support patients with the financial burden of living with PIDs and SIDs

- The Government should review the prescription charge **exemption list** with a view to adding patients living with PIDs and SIDs
- Information relating to financial assistance should be promoted and made more accessible to patients by healthcare professionals and, wherever possible patients should be signposted to patient groups for further support

Awareness of non-clinical support

RECOMMENDATION

To reduce inequalities relating to psychological support, health leaders should ensure that tailored mental healthcare – either provided by the NHS or through external organisations – is built into service planning and included in personalised care plans for people living with PIDs and SIDs

Introduction

In a major survey conducted by IDUK in 2016, many respondents expressed frustration with delays in diagnosis and difficulties accessing appropriate care for their condition. Whilst the report highlighted the breadth of good work being done across the country, several challenges were identified, including delays in diagnosis, the significant impact of immunodeficiency on people's everyday lives and poorly co-ordinated care with multiple different healthcare professionals and touchpoints involved in the management of complications of immunodeficiency.[3] IDUK made five recommendations targeted at those providing immunodeficiency services across the UK.

PIDs cover more than 450 rare, chronic disorders in which genetic abnormalities result in a malfunctioning immune system. Approximately 20 of these disorders account for over 90% of cases; for some conditions, fewer than ten cases have been identified.[4]

SIDs occur when the immune system is weakened by another treatment or illness, such as blood or bone marrow disorders, some cancers or drugs (medicines) and treatment for cancer. Other factors, such as malnutrition, can also cause SID.[5]

People with PID and SID are vulnerable to recurrent infections which can be life-threatening. Managing their condition can require constant vigilance and specialised medical care.

Seven years on, our 2023 experience survey of patients living with PID and SID reveals little has changed in many areas.

We uncovered the distressing and unacceptable reality that only 52% of respondents (n=288)[1] reported a good, or very good, quality of life following their diagnosis.

This report will show that securing a diagnosis is hard enough for so many patients. It cannot be right that, even after that point, 1 in 2 patients do not feel positive about the quality of their life.

The 2023 survey also finds significant variation in:

- Involvement in treatment decisions
- Awareness of peer and psychological support options
- Recovery, both physical and emotional, from the COVID-19 pandemic

Since the 2016 survey, the country has been through the COVID-19 pandemic—a period that deeply affected many people living with PID and SID, who experienced significantly higher morbidity and mortality than the general population.[6] Whilst it seems that life has returned to 'normal' for most people, the anxiety and real risk of infection remains for many with immunodeficiency, compounded by the – often daily – challenges they experience in accessing care and support.

People living with PID and SID have been misunderstood and underserved for too long. With the NHS front and centre of public attention, it is time to make sure patients living with PID and SID are properly supported. The situation is urgent.

Methodology

To understand the experiences of patients with PID and SID of their care, IDUK collaborated with Takeda UK Limited and Interaction Marketing & PR to conduct a voluntary online survey – consisting of multiple choice and free text questions – of 298 PID and SID patients and care givers across the four nations of the UK, fully funded by Takeda UK Limited. Open between July and September 2023, the results from the survey were later collated by independent healthcare communications consultancy Interaction Marketing & PR in accordance with UK Data Protection Law.

Following data collection, survey results were analysed by a specialist healthcare policy and communications agency, Incisive Health, to identify trends and formulate evidence-based recommendations. Qualitative free text responses were also analysed to uncover key themes in patient experience and have been used throughout this report to supplement and contextualise our recommendations.

The survey captured valuable data on the views of patients, however we have also been cognisant of the following points in our analysis of the data:

- The variation in age of respondents was not reflective of the overall population of those with PID and SID in the UK. for example, while approximately 17% of PID patients are younger than 16 in the UK,[7] just 2.4% of respondents were within this age bracket
- The sample size of 298 for this survey comprised a small percentage of the total population in the UK with PID and SID who receive immunoglobulin therapy (6,557 in 2022/23)[8] so may not be fully reflective of individual aspects of care which patients receive
- Some older respondents may provide details of their experience with diagnosis and treatment when they first received this – in some cases over a decade ago – and therefore may not be reflective of the current state of care
- Phrasing of individual questions are subject to misinterpretation
- Respondents were not required to provide answers to every question within the survey, and therefore not all respondents completed all questions within the survey

2023
survey findings

Patients living with PID and SID answered questions on a wide range of topics including the care and support that is, or should be, available to them. Through our analysis, we identified three key areas across the PID and SID patient pathway within which the widest variations exist and where urgent action is needed:

1. **Symptom awareness and diagnosis**
2. **Experience of the care pathway**
3. **Awareness of non-clinical support**

Through this report, we take each of these in turn and provide recommendations to health leaders and professional organisations across the UK on how improvements can be achieved.

1 Symptom awareness and diagnosis

Regardless of condition, securing a fast diagnosis is crucial to helping patients begin their care journey positively. Underscoring its importance, the Government has set out faster diagnosis as a key priority for rare diseases in their 2025 Rare Diseases Action Plan[9] – almost all PID conditions fall into this category.[10,11]

Delayed diagnosis has long been a major hurdle for patients with PID and SID. In part this is because many symptoms of PID and SID mimic those of other immune conditions,[12] but it is also a result of limited understanding of these conditions among healthcare professionals across specialities.[13] Delays in securing a diagnosis mean that many of these patients must live, unnecessarily, with physical, and often severe,[14] symptoms of PID and SID and emotional distress before starting treatment, as well as starting their treatment at a later stage when their condition has likely worsened.[15]

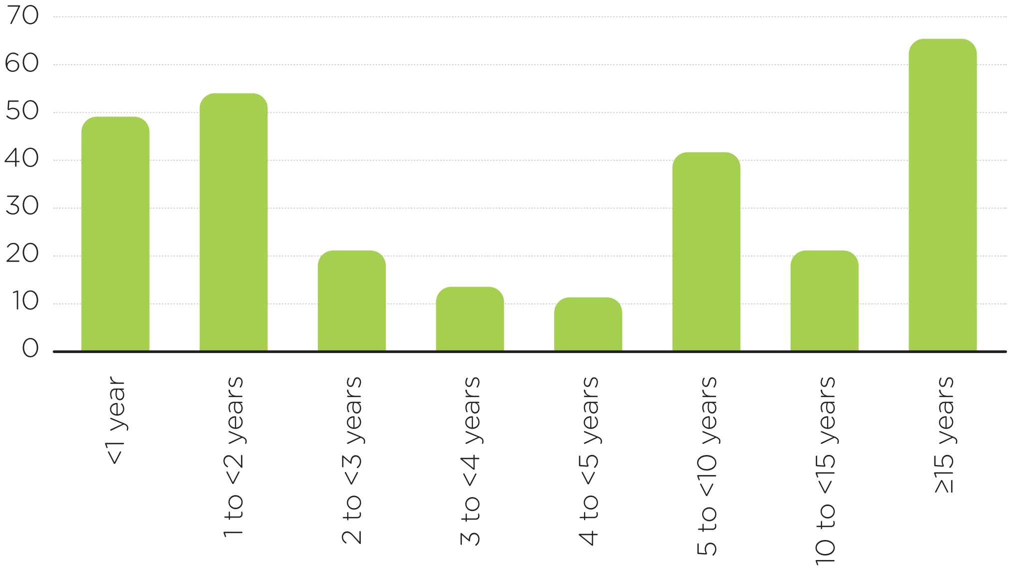
Time to diagnosis

The findings of the 2023 survey underline the magnitude of this issue. **Only 37% of respondents (n=277) were able to secure a confirmed diagnosis within 2 years of experiencing symptoms, rising to 53% within 5 years. 24% of respondents experienced symptoms for over 15 years before receiving their diagnosis** (see figure 1).[1]

A notable variation in time to diagnosis among survey respondents was found between those with PID and SID. 54% of those with SID (n=65) were found to have received their diagnosis within 2 years, compared to just 32% for patients with PID (n=212).[1] On the other end of the scale, **6% of patients with SID who responded to the survey waited more than 15 years for a confirmed diagnosis, which is almost five times fewer patients than those who had to wait 15 years with PID (29%) (n=212).[1]**

Understanding the potential causes behind these delays in diagnosis will be key to improving swift access to care and improving patient experience.

Figure 1: How long were you experiencing symptoms before you were diagnosed (n=277)?



A notable majority of patients experienced symptoms for multiple years before securing a diagnosis

> *It took many frustrating years and infections before a GP finally twigged there was likely to be an underlying cause. Even then it took 2 more years before getting to a diagnosis.*

Appointments and admissions before diagnosis

This issue is not only about the time it takes to secure a diagnosis, but also the inconvenience, frustration and distress created by patient interactions with the health service during this time that fail to uncover the cause of symptoms.

Of survey respondents, **54% attended 10 or more appointments** with a healthcare professional for their symptoms, with **14% attending 50 or more appointments** before their condition was diagnosed (n=241). In most cases, respondents reported attending more than one appointment with a healthcare professional with conditions and symptoms in relation to their condition prior to receiving a diagnosis.[1]

> ***Not being diagnosed until I was 60 was a problem. I was always told the infections were just one of those things no one understood.***

In addition, patients with PID frequently reported attending more appointments before receiving a diagnosis compared to those with SID. Of those that attended prior appointments, **60% of PID patients (n=183) attended 10 or more appointments, compared to 38% for those with SID (n=58).[1]**

While the overall figures across demographics represent an improvement on data from 2016, which indicated approximately half of survey respondents attended 10 or more appointments before being diagnosed,[3] this data highlights just how stark these challenges remain for patients.

Aside from their GP, the five clinics most commonly visited by patients prior to receiving a diagnosis for PID or SID included: respiratory specialist; immunologist; haematologist; rheumatologist; and allergy specialist (n=298).[1]

During these extremely difficult and lengthy waits for a diagnosis, it is also common for patients to be admitted to hospital with symptoms connected to PID and SID. 55% of respondents had been admitted to hospital before their confirmed diagnosis (n=297).[1] Of those who responded, **14% were admitted at least 10 times while 5% were admitted at least 20 times (n=150).[1]**

> *There is so little understanding of the condition within the medical profession and instead of trying to learn about it and understand it they totally ignore it.*

RECOMMENDATION

To enable patients to secure a timely diagnosis:

- NHS leaders should work with professional organisations to promote and improve accessibility – particularly for GPs – of existing resources on **warning signs** and identify needs for additional resources, such as a digital tool, to improve symptom awareness
- NHS leaders should work with patient groups to conduct a review of patients diagnosed with PIDs in the past five years to assess the time taken and blockers to securing a diagnosis
- Professional groups should expand representation for primary care in initiatives to drive improvements in care for patients with PIDs and SIDs

2

Experience of the care pathway

Securing a diagnosis for PID and SID is the first significant hurdle for many patients, but as the 2023 survey reveals – and was also the case in 2016 – that it is far from the last.

Despite professional bodies agreeing upon key standards of care – including the British Society of Immunology Clinical Immunology Professional Network (BSI-CIPN) and Royal College of Physicians Quality in Primary Immunodeficiency Services (RCP QPIDS) – we hear from patients themselves that experiences of care, following a diagnosis, vary greatly with factors including where they live, the quality of services in their local area, and the healthcare professionals they engage with. While there are always likely to be variations in care across the UK, the survey identified issues that are seemingly prevalent in all services impacting on patient experience.

Communication between healthcare professionals

Continuity of care and communication between healthcare professionals as patients progress through the pathway, from initial suspicion to beginning treatment and long-term management, is vital to ensuring information regarding treatment preferences are continually taken into consideration at every stage of the pathway. As people with PID and SID frequently interact with a wide range of healthcare professionals, their experience of their care can be greatly impacted by how well information about their care is recorded and communicated.

The survey found that 23% of respondents strongly agreed that the different healthcare professionals involved in their diagnosis communicated with each other effectively, whereas 24% strongly disagreed with this statement (n=293).[1]

While a higher proportion of respondents with SID (n=71) strongly agreed with the statement that healthcare professionals involved in their diagnosis had been more effective than respondents with PID (n=221) (39% vs 18%),[1] overall figures suggest that much more could be done to ensure every patient receives the necessary and valued communication with healthcare professionals.

Effective communication between, and thinking outside the boundaries of, different parts of the health service is important for ensuring patients receive high quality care and feel confident in their healthcare.[16] For patients living with immunodeficiency, we have previously heard that poor communication can force patients to navigate and coordinate their own care, often when they have the least energy to do so.[3]

Patient involvement in treatment decisions

The NHS and several healthcare think tanks advocate for patients to be involved in their care, citing benefits such as better decision making, improved health and health outcomes, and resources being allocated more efficiently.[17,18,19] We also know that involvement can help to empower patients to take a more active role in maintaining a healthy lifestyle and self-monitoring their condition, further contributing to a better quality of life.[20]

While patient involvement in treatment decisions and their wider care is enshrined within the NHS Constitution[21] and National Institute for Health and Care Excellence (NICE) clinical guidelines,[22] the survey suggests that involvement remains inconsistent, potentially resulting in patients being on treatments that do not accommodate their preferences.

86% of respondents (n=279) felt their lifestyle, personal preferences, cultural beliefs and right to choose were either somewhat respected or respected a great deal while deciding treatment options.[1]

Positively, this has improved from 76% in 2016.[3] In addition, 83% of respondents (n=240) noted that they were offered a choice on the route of their immunoglobulin therapy,[1] an improvement from 2016 when just 65% said they were offered a choice.[3]

This progress is welcome, but must go further – **with almost a fifth of respondents stating that they were either not at all involved, or not much involved in decisions regarding their care or treatment (n=292),[1]** we believe that every patient should feel involved in decisions about their care. In addition, while the survey found improvements in how many treatment decisions took into account lifestyle factors and patient preferences, the 2023 survey uncovered a decrease in the proportion of respondents noting that they were encouraged to participate in decisions regarding their care plan/treatment at 81% in 2023 (n=292),[1] a 6% reduction from the 2016 survey.[3]

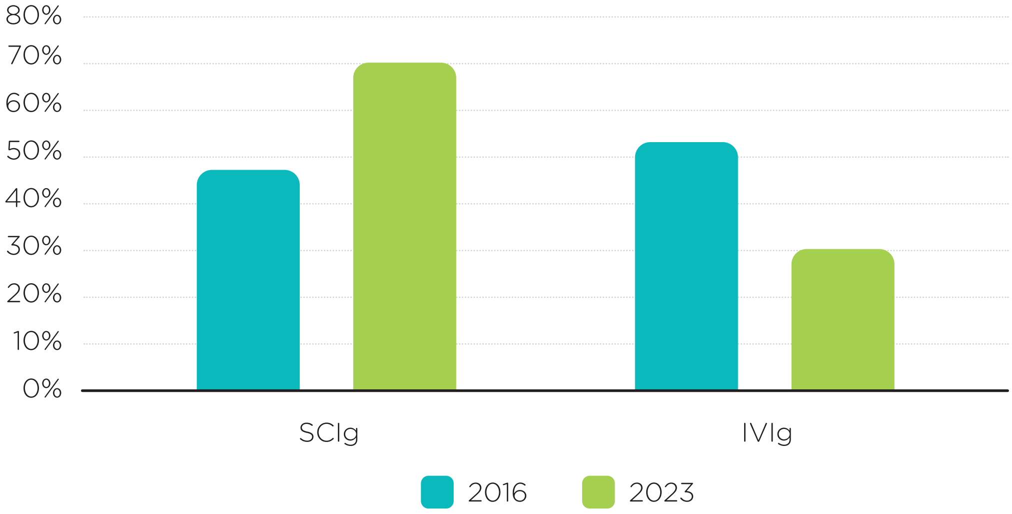
Route and location of treatment

Depending on their condition, most patients have two options for the routes to administer their immunoglobulin treatment: intravenously (IVIg) which is usually delivered in hospital, or subcutaneously (SCIg) which can be administered at home.

As noted in BSI-CIPN guidelines it is important that patients, where clinically appropriate, are provided with a choice of how and where to receive their immunoglobulin therapy, to minimise the impact on their life and reflect their preferences.[2]

Through the survey, we uncovered a rise in the proportion of patients receiving their treatment subcutaneously from 2016 (70% up from 47%), **as opposed to intravenously** (30% down from 53%) (n=235) (see figure 2).[1,3] Not all patients can be, or are, offered a choice – when respondents were offered a choice, 68% elected for SCIg and 32% elected IVIg (n=194).[1]

Figure 2: How do you receive your immunoglobulin therapy?



A greater proportion of respondents noted that they received their immunoglobulin therapy subcutaneously in 2023 than in 2016

A majority of respondents overall rated their experience with the care they received as either good or very good regardless of whether or not they were offered a choice between IVIg or SCIg (n=230).[1] Over 80% of all patients were offered a choice on the route of treatment administration (n=240), with 16-34 year olds being the age group consulted less often (n=12). The percentages for each age group were as follows: Under 16: 80% (n=5), 16-34: 57% (n=21), 35-49: 92% (n=50), 50-64: 82% (n=78), 65-74: 76% (n=71), 75 and over: 83% (n=12).[1]

69% of respondents reported that they currently receive SCIg (n=236),[1] which tended to be delivered at home rather than in hospital.[1] When asked about the location in which they receive their treatment as a whole – regardless of route of administration – 25% of total respondents noted they receive this in hospital (n=234),[1] down from 45% in 2016.[3] Of those respondents that were offered a choice regarding their treatment location, a greater proportion received their treatment at home – 78% (n=190) compared to 62% for those who were not offered a choice (n=42).[1]

When asked about their personal experiences of the care they received, a greater proportion of respondents rated their experience as very good when they had been offered a choice of where to receive their treatment (61%) (n=184), compared to those who were not given a choice (44%) (n=45).[1]

Additionally, patients should receive an annual review of their care, including administration and location in line with BSI-CIPN guidelines,[2] which helps to ensure the safety and quality of care and that patient preferences are understood. However, 19% of patients reported that their homecare treatment was not regularly reviewed (n=100).[1]

77% of respondents reported having their homecare treatment reviewed once a year,[1] as per clinical guidelines,[2] leaving 23% who were not (n=93).[1]

Long-term management

Effective long-term management of PID and SID is instrumental in supporting a good quality of life. This requires patients to be well educated on their condition, including knowing how to identify potential issues or complications, what to do in the event of a complication and who to contact.

Survey findings showed a high proportion of individuals felt well-equipped with educational resources and requisite knowledge to manage their condition in the long-term. 90% of respondents (n=292) said they had been told of potential problems or complications to look out for following diagnosis and 90% (n=290) had been provided with information on what to do and who to contact if problems occur.[1]

However, it should not be overlooked that this suggests that around 1 in 10 may not have received such guidance.[1]

Understanding why these patients do not feel supported and identifying ways to help will be important in helping them to improve their experience of the care they receive and management of their condition.

> *I need to be able to contact someone occasionally to ask pretty simple questions but these questions can cause a lot of anxiety.*

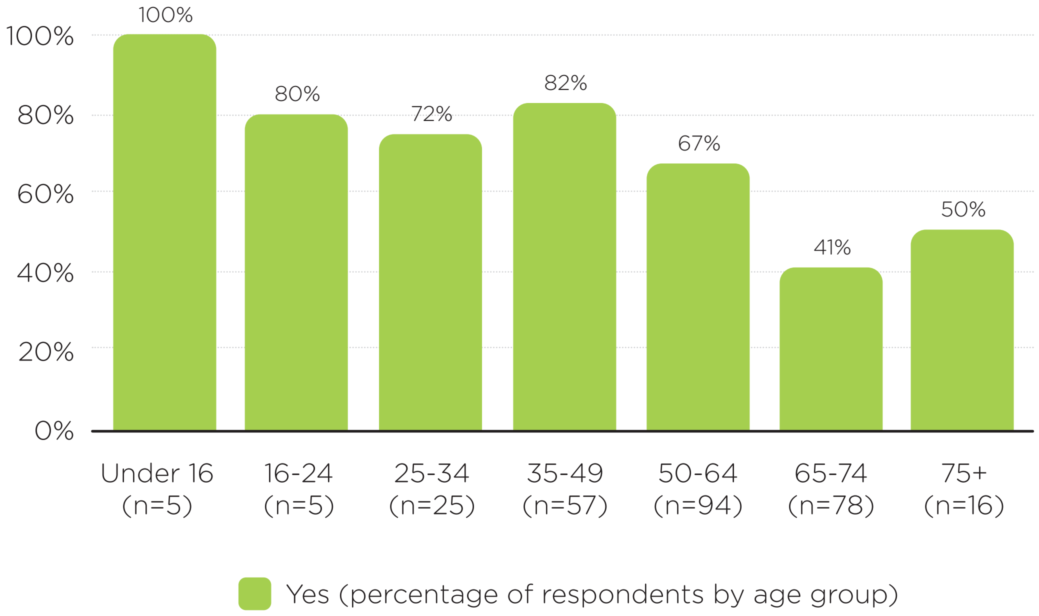
Financial impact

The financial costs for individuals associated with living with PID and SID can be numerous and far reaching, including transportation costs, prescription charges, loss of wages and additional childcare costs.[23] As the cost-of-living crisis persists, and expenses associated with PID and SID increase with inflation, patients are increasingly facing financial difficulties which impact their physical and emotional wellbeing.

The survey showed an increase in the proportion of respondents facing extra expenses due to their condition, rising from 59% in 2016 to 63% in 2023 (n=281).[1,3] Additionally, survey results suggest that the financial impact was felt more deeply as age decreased (n=280) – while relatively few respondents were under the age of 24 (n=10), over 80% noted facing additional expenses compared to 50% or below for those aged 65 or over (n=94).[1]

While most patients incur additional expenses related to their condition, **83% of respondents across all age brackets were unaware of any financial support available to them.[1]** More patients with SID (n=68) demonstrated greater awareness of this support than those with PID (n=210), although this was still only the case for 25% of patients.[1]

Figure 3: Do you face extra expenses due to your condition?



The proportion of patients in each age bracket facing additional expenses due to their condition decreased with age

RECOMMENDATION

To drive improvements and reduce variation in care across the country:

All primary immunodeficiency services should strive to achieve the Royal College of Physicians' Quality in Primary Immunodeficiency Services (**RCP QPIDS**) accreditation. Doing so would require them to increase focus on areas including:

- Providing regular opportunities for patient / carer feedback
- Ensuring person-centred support based on individual need
- Monitoring and reporting on quality metrics
- Ensuring appropriate facilities and equipment are made available and information and training provided for home therapy

All services should adhere to standards set out in the UK Primary Immunodeficiency Network (UK-PIN) and the British Society of Immunology (BSI) **consensus statement,**[2] including:

- All patients should be able to choose how their immunoglobulin treatment is administered and to have treatment at home, where clinically appropriate
- Patients with PID who are established on IgRT and have no complications should be monitored at an immunology specialist clinic at least every six months

National policymakers should work with the patient community to develop an assessment in relation to patient quality of life for local services to complete on an annual basis

RECOMMENDATION

To support patients with the financial burden of living with PIDs and SIDs:

- The Government should review the prescription charge **exemption list** with a view to adding patients living with PIDs and SIDs
- Information relating to financial assistance should be promoted and made more accessible to patients by healthcare professionals and, wherever possible patients should be signposted to groups for further support

3

Awareness of non-clinical support

Non-clinical support and access to a network for patients can be instrumental in improving their wellbeing and quality of life.[24] Peer support and community groups, financial assistance[25] and educational resources[26] are some examples of the types of support that can ensure patients have a better experience at each stage of their journey and maintain positive emotional wellbeing.

This support is typically not provided by the NHS or local trusts – instead, patients are usually directed to, or must search for, external organisations, such as charities and patient organisations, who offer support. The survey uncovered varying levels of awareness of these services, suggesting limited or poor signposting from healthcare professionals within the clinical pathway.

Immunodeficiency UK offers a wide range of support for patients, including:

- *A helpline*
- *Advice on eligible benefits and financial assistance*
- *Educational resources on how to live well with immunodeficiency*
- *Support for patients, including for carers, parents, children*
- *Guides on available treatments*
- *Mental health support programmes*

Peer support

Peer support – involving interactions with others facing similar conditions – can be a key factor in maintaining a high quality of life and positive psychological and emotional wellbeing.[27]

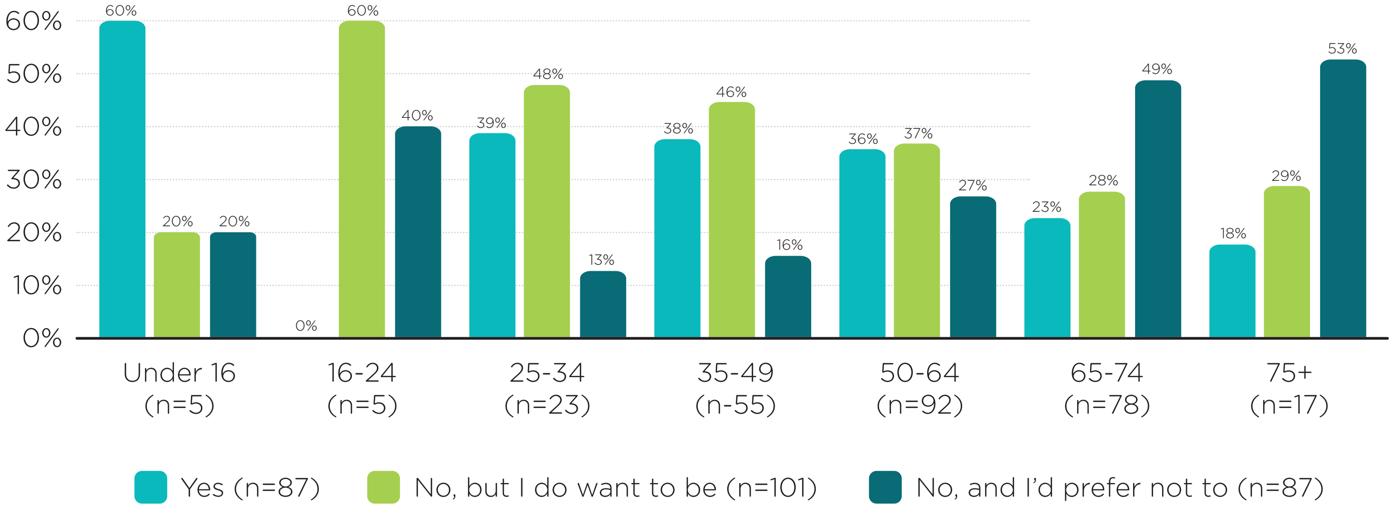
The survey found that 7 in 10 respondents were not in contact with other patients living with similar conditions (n=291),[1] as well as a disparity in peer support among those who receive treatment at home vs those who receive treatment in a hospital setting. A lower proportion of respondents were found to be in contact with other patients with similar conditions when receiving care at home relative to those receiving treatment in hospital (28% vs 43%) (n=231).[1]

Further analysis also found that the proportion of respondents reporting being in contact with other patients with similar conditions was generally higher in the younger age groups (60% in under 16s (n=5) vs 18% in 75 years and over (n=17)), except for in the 16-24 age group (n=5) where none of the patients reported being in contact with other patients with similar conditions (n=290).[1]

Of respondents that were not in contact with other patients, generally a greater proportion of younger respondents (excluding those under 16) reported wanting to be in contact with other patients (60% of 16–24-year-olds (n=5) vs 36% of 75-year-olds and over over (n=14)).[1]

The small number of respondents in some age groups (under 16 and 16–24-year-olds) may have impacted the results. (see figure 4).[1]

Figure 4: Are you in contact with other patients with your condition?



Psychological support

As a long-term – or even life-long – condition, patients with PID and SID are at risk of developing poor emotional and psychological wellbeing, with the impact of their treatment taking a toll on all aspects of their lives.[28]

The medical care that patients need can itself have psychological effects, e.g. via the disruption and anxiety caused by clinic visits, medical tests and hospital admissions (e.g. for infections) and concerns about the side effects of long-term treatments. Psychological support can therefore be a key tool to help patients maintain a high quality of life.

In 2021, a survey of PID services across the UK found that just 2 of 22 responding centres reported having a dedicated psychologist for clinical immunology patients, and just 8 of those remaining centres reporting an 'effective' psychology referral pathway.[29] In addition, many patients who responded to the 2023 survey reported that information about psychological services is not routinely made available.

In 2016, just a quarter of respondents reported having access to additional specialist services for example: psychological support, social care etc.[3] In 2023, 53% of respondents overall were not aware of support to help with fear and anxiety related to their condition, leaving less than half of patients aware of this support (n=293).[1]

The most requested source of support was mental health services and counselling (37%) followed by access to written disease information (33%) and treatment information (32%) (n=266).[1] IDUK was the most commonly mentioned support charity respondents were aware of to access additional support services with 14% noting this (n=116).[1] Given how critical services such as mental health treatment, counselling, access to written disease information are for patient wellbeing, effective communication between the NHS and external providers and charities is vital. With limited capacity in both NHSE and external mental health services for immunocompromised individuals and those with rare diseases, ensuring patients are appropriately prioritised and directed to the most suitable support is key to improving access and reducing waiting times for these services.

> *I had a good quality of life, going on holiday abroad, many social activities with various friends/family but since Covid... my former life is now non-existent and I rarely go out.*

Impact of COVID-19

Psychological support can play an important role in maintaining quality of life, especially when additional pressures – such as those linked to COVID-19 – intensify stress.[30] While social distancing and shielding regulations introduced during the COVID-19 pandemic provided the public with reassurance and safer environments, it presented unique challenges for people with immunodeficiency, who were particularly vulnerable to experiencing serious complications and mortality from the virus.[31]

> *[I] don’t feel able to enjoy life fully due to the impact of Covid.*

While lockdowns eased and the country reopened, the impact of the pandemic continued to be felt by many PID and SID patients. Following the pandemic, the survey found a notable increase in feelings of isolation, anxiety and stress as these patients readjust and reintegrate into post-pandemic society.

77% of respondents reported that they had experienced increased feelings of vulnerability due to COVID-19, 57% experienced increased feelings of loneliness, and 37% experienced depression during the pandemic (n=268).[1]

Although the final national lockdown was lifted in July 2021, two years on 79% of respondents still felt either somewhat or much more susceptible to infections because of the pandemic (n=284).[1]

Respondents also noted having experienced increased feelings of security due to social distancing (34%) and reduced anxiety due to (34%) lockdown measures (29%) (n=268).[1] As patients continue to reintegrate into post-pandemic society and recover their quality of life, there remains a huge amount to be done to ensure they are supported to regain confidence and manage the anxieties exacerbated by the pandemic, including provision of, and better access to, counselling and emotional support services.

> *Feel like I haven’t got my life back to how it was pre-pandemic.*

RECOMMENDATION

To reduce inequalities relating to psychological support, health leaders should ensure that tailored mental healthcare – either provided by the NHS or through external organisations – is built into service planning and included in personalised care plans for people living with PIDs and SIDs

Looking to the future

Every patient has a unique experience of, feelings about, and preferences for their care. But it is clear from our latest survey that there is both necessity and opportunities to take steps that would improve the lives of many living with PID and SID – both those with and currently without a diagnosis. We cannot accept the length of time and effort it takes to get a diagnosis nor that only half of the known patient population for PID and SID say they have a good quality of life.

From diagnosis through to long-term management and support, the importance of finally tackling issues that undermine patient experience and damage health outcomes cannot be understated. Improving awareness among healthcare professionals of the symptoms and needs of PID and SID, ensuring adherence to clinical guidelines, and providing comprehensive information on support and resources available to patients for their condition, are all valuable steps that must be taken.

Immunodeficiency UK, together with Takeda, reaffirm our commitment to listening to patients and working with them to assess where further support is needed to have a meaningful impact on their lives. To compensate for the 7 years of inaction since our last survey in 2016 and to enable all patients with PID and SID to have a good quality of life, we now need the same commitment from policymakers and health system leaders across the UK.

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Supporting families affected
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