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Supporting families affected
by primary and secondary
immunodeficiency

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Behind the switch: insights into IG therapy changes across the UK

Evidence and insights from patients and healthcare professionals across the UK, exploring how immunoglobulin (IG) therapy switches are experienced in practice and what this means for care and delivery.

June 2026

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Foreword

The periodic implementation of new NHS immunoglobulin (IG) commissioning frameworks frequently alters the availability of IG brands. Consequently, significant numbers of people who rely on IG therapy to treat their primary or secondary immunodeficiency have to switch from their usual IG product to another. This survey report examines the impact of 2025 NHS IG commissioning decisions on both patients and the healthcare professionals involved in their care.

This report has been made possible thanks to the contributions of patients, carers and healthcare professionals who shared their experiences. We are especially grateful to those who provided detailed free-text responses that gave valuable insight into the realities of switching IG product. Thank you!

These perspectives have added depth to the quantitative findings in this report and have helped to highlight the human impact of system-level decisions. To ensure these insights are fully recognised, the qualitative responses have been collated and are available alongside this report as part of the wider body of work. We hope this will allow stakeholders to engage more directly with the lived experiences described by respondents, complementing the analysis presented here.

You can access these responses **here.**

Collectively, the report findings reveal an opportunity for the NHS to foster a more balanced and sustainable approach to IG therapy management. Aligning system priorities with the experiences of those directly affected should be central to future decision-making, and is essential to improving both patient and service outcomes.

Dr Susan Walsh

CEO, Immunodeficiency UK

Executive Summary

IG therapy switching is now routine - but how it is implemented is shaping patient experience, frontline workload and service sustainability

What is the issue?

IG therapy switching is now routine across parts of the UK, largely driven by system-level changes to how therapies are commissioned and supplied following the introduction of the NHS commissioning framework.

While switching is increasingly embedded in practice, how it is implemented is shaping patient experience, frontline workload and service sustainability.

Both patients and healthcare professionals highlight a consistent theme: switching often occurs despite patients being stable and satisfied on their existing therapy.

> ***I was happy with the old product I didn't have reactions to it and I feel it suited me and I didn't want to change.***

> ***Organisational driven changes cause more stress/anxiety for patients as generally they are happy with the product they are currently receiving and there is always some concern for them surrounding changing products unnecessarily.***
>
> ***Clinical Nurse Specialist***

What this report reveals

System-driven switching*

Patients report limited involvement, lack of choice and unclear explanations when system-driven switches occur.

Early support matters

Patient confidence builds over time, but first impressions matter most. Clear **communication and support at the point of switching are critical.**

Frontline teams impact

HCPs deliver switches, manage training and provide reassurance, despite **limited involvement in upstream decision-making.**

Why this matters?

Patients experience increased anxiety, disruption and delayed confidence

Services undergo an additonal workload, time pressure and avoidable demand

What needs to change?

- Embed patient-centred communication and shared decision-making
- Align system decisions with frontline capacity and realities
- Treat switching as a supported transition, not a single event

Key takeaway

Immunoglobulin therapy switching is not just a clinical change, it has system-wide implications.

Where patients feel they are more informed, involved and supported, their experiences and outcomes of switching are significantly improved.

**System-driven switching refers to therapy changes driven by commissioning, procurement, supply or policy decisions, rather than individual patient need or preference. These decisions are typically made upstream and implemented by frontline clinical teams.*

Introduction

Immunoglobulin (IG) therapies are a cornerstone of care for people living with primary and secondary immunodeficiency, playing a vital role in preventing infection and maintaining quality of life. **Over the past year, the landscape of IG provision across much of the UK has evolved following the introduction of a new NHS commissioning framework governing the supply of IG products.** Designed to support continuity and resilience of supply, the framework has also brought changes in the availability of certain IG products, which has, in turn, contributed to an increased frequency of patients being asked to switch therapies.

Crucially, arrangements for IG supply and commissioning are not uniform across the UK. **The commissioning framework applies in England and has been implemented in Scotland and Northern Ireland. Wales, however, has not participated in the framework, operating instead under its own established IG supply arrangements.** This divergence creates materially different contexts in which IG therapy switching occurs.

Survey findings suggest that in nations aligned with the commissioning framework, switching is frequently linked not only to clinical considerations but also to wider system-level factors, including supply management and commissioning structures.

By contrast, in Wales, switching appears more consistently driven by clinical need alone. These differences are significant, as they shape both the decision-making environment and the lived experience of switching for patients and healthcare professionals.

Against this backdrop, this report presents findings from two complementary surveys exploring experiences of IG therapy switching from the perspectives of patients and carers, and healthcare professionals (HCPs). **The findings highlight how switching is experienced in practice, the impact of system-level change on care delivery, and the practical and emotional implications for those involved.**

By examining themes including communication and involvement, confidence over time, treatment burden, and service pressures, and by considering variation across UK nations, this report contributes evidence on how IG therapy switching is currently being managed and what is required to ensure that processes remain both operationally sustainable and grounded in clinical need and patient experience.

Methodology

Both surveys were open over the same 12-week period (16/10/2025–09/01/2026) and comprised a combination of closed-ended and open-ended questions. This supported a comprehensive exploration of the barriers, challenges, reported outcomes, and real-world impacts associated with immunoglobulin therapy switching.

Patients and carers

The patient survey was designed to capture the experiences of individuals living with primary or secondary immunodeficiency who are receiving IG therapy, as well as carers or family members responding on their behalf.

In total, 297 responses were received.

Geographic distribution

77.5% (230) of patient respondents were from England, 8% (24) from Scotland, 4% (12) from Wales and 2% (6) from Northern Ireland. 8.5% (25) did not specify.

Age groups

Responses received most from individuals aged over 60 years (40%), followed by 46-60 years (29%).

Respondent type

9% of respondents were family members or carers responding on behalf of a patient, and the rest were patients themselves.

HCPs

The HCP survey was designed to capture perspectives from professionals involved in the delivery and management of IG therapy switching.

As with all survey-based research, the findings should be interpreted in light of certain limitations. Participation was voluntary, and may therefore reflect the views of individuals with particularly strong experiences of therapy switching.

In addition, the sample size for the healthcare professional survey was smaller than that of the patient survey, and findings should be considered within this context.

In total, 55 responses were received.

Geographic distribution

76% (42) of HCP respondents were from England, 13% (7) from Wales, 7% (4) from Scotland and 4% (2) from Northern Ireland.

Professional roles

The most common roles were Clinical Nurse Specialists (49%) and consultants/doctors (36%), with other roles (15%) including Immunology Nurse, Pharmacist, Ward Sister and Advanced Nurse Practitioner (ANP).

Patient survey- key findings

1 Reasons behind switching

Patients most commonly reported that IG therapy switches were driven by system-level factors, rather than by individual clinical need or patient preference, a finding that is consistent with the wider commissioning framework shaping IG supply in England, Scotland and Northern Ireland.

Among respondents who answered the question ***"What were your/the main reasons for switching?"***, the most commonly reported reasons were supply or availability issues, NHS policy changes, and financial considerations, as illustrated in Figure 1. Other reasons, including clinical factors, changes to how or where therapy is administered, and patient preference, were reported less frequently.

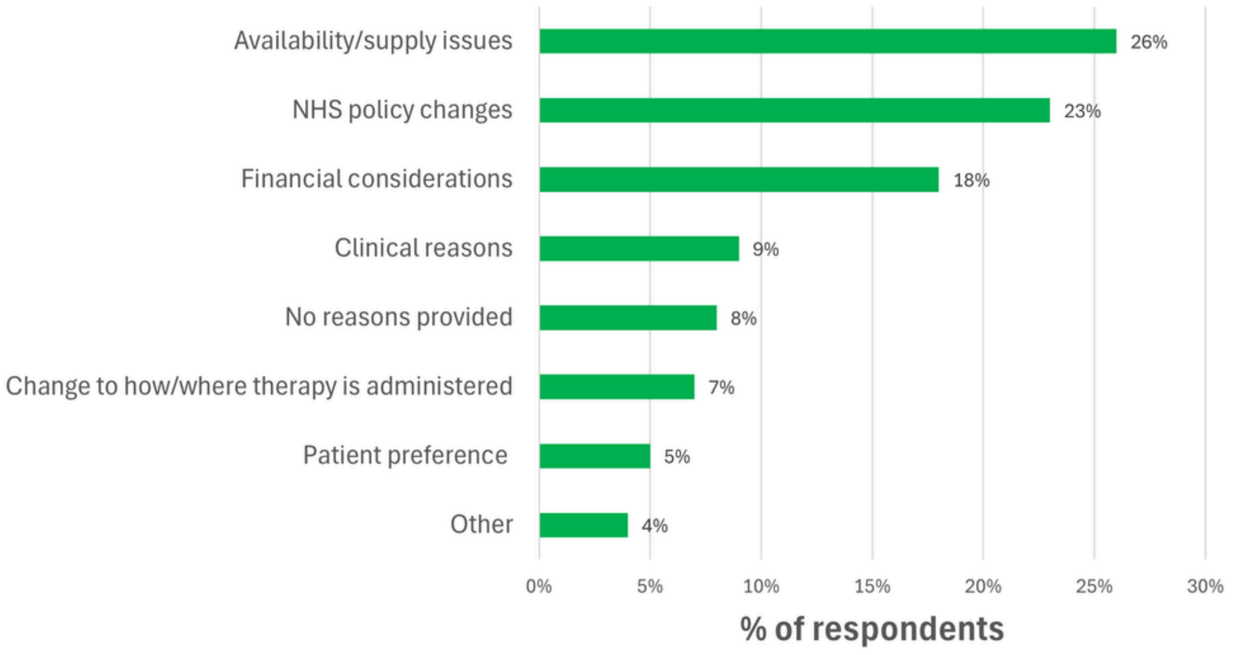


Figure 1: Reasons for switching immunoglobulin therapy

> ***Product switch mandated by NHS policy.***

> ***Because my old medication was being withdrawn, and I had to switch onto a new brand. There was no choice, but I did feel informed.***

Patient survey- key findings

1 Reasons behind switching

By contrast, a smaller proportion of patients reported switching for clinical or patient-specific reasons. Among Welsh respondents who had switched therapy, a higher proportion (44%) reported that the switch was due to a clinical reason, compared with respondents in England (8%).

This aligns with differences in commissioning arrangements, where **switching in Wales is more typically driven by clinical need**, resulting in fewer patients being required to switch overall and therefore a smaller number of Welsh respondents reporting a switch (n=9 vs n=186 in England).

For many respondents, IG therapy was described as a long-term or lifelong treatment that had been carefully integrated into daily life over a considerable period of time. Against this backdrop, switching was often experienced as a significant disruption rather than a routine adjustment.

This pattern is further reinforced by qualitative responses, in which **many patients described switching as something that happened to them, rather than as the outcome of a collaborative clinical discussion**. Together, the quantitative and qualitative findings indicate that patients often perceive therapy switches as externally driven, with limited opportunity for shared decision-making.

> ***It always reminds me I am not in charge of my illness and I have very little choice on what happens to me. Makes me feel helpless.***

> ***It wasn't a discussion; it was an instruction to come in for a brand switch on a particular date.***

2 Communication, involvement and shared decision-making

There was a consistent call for stronger communication and more meaningful involvement in decisions to switch IG therapy across patient's responses.

When asked "***Were you informed and involved in the decision to switch?***", just over half of patients (51%) reported that the switch was discussed with them. However, **a substantial proportion described limited or absent involvement: nearly one third of respondents (32%) stated that the decision was made without their involvement, while a further 17% reported that the switch was mentioned but not discussed in detail.**

These findings are reinforced by responses to the question "***Did you feel you had a choice in the decision to switch?***" **Almost four in five patients (79%) reported that they did not feel they had a choice**, highlighting a widespread perception that switching was externally driven rather than the result of shared decision-making.

Clarity of explanation also emerged as a key factor in shaping experience. In response to ***"How clearly was the reason for switching explained to you?"***, just over half of patients (53%) reported that the reason was explained very clearly, while more than one in five (21%) felt the explanation was unclear or absent. **This suggests that clear information alone does not guarantee meaningful involvement, particularly where patients feel unable to question or influence their own care decisions.**

Patients who reported clearer explanations and greater involvement in discussions tended to describe more favourable experiences of the overall switching process.

Key statistics

- **49%** of patients did not feel meaningfully involved in the decision to switch
- **79%** of patients felt they had no choice in switching
- **21%** felt the reason for switching was unclear or not explained
- **32%** of patients felt that the decision to switch was made without their involvement
- **17%** of patients reported the switch was mentioned to them but not discussed in detail

3 Impact on a patient’s daily life

Patients who had experienced a switch were asked about the effect this had on their daily lives and emotional wellbeing. Respondents outlined a range of practical and personal consequences, identifying the following key areas:

Additional appointments and travel

50% of patients required additional appointments and 36% experienced additional travel, often linked to training needs, and monitoring following the switch.

Time off work

25% of patients reported needing to take time off work, reflecting the additional time required to attend appointments, undertake training, or manage disruptions associated with switching.

Extra costs

31% of patients incurred out-of-pocket costs, including expenses related to travel, parking, and other incidental costs associated with attending additional appointments.

These impacts were frequently experienced in combination, contributing to disruption of established routines and increasing the time and effort required to manage treatment.

Notably, **around 60% of patients reported experiencing at least one additional burden as a result of switching**, underlining that the impact commonly extends beyond the clinical setting and into everyday life.

Requirements such as additional appointments, increased travel, time off work and out-of-pocket costs represent significant and tangible consequences for patients. **These impacts are not incidental**; they shape the overall experience of switching and influence how manageable treatment feels in practice. While commissioning decisions operate at a system level, the practical and financial implications are often borne directly by patients, making this a critical consideration in the implementation of switching policies.

Patients emphasised that **the true burden of switching lies not only in the infusion itself, but in the surrounding planning, coordination, and adjustment required.** Where training, follow-up, or coordination were limited, these practical demands were often accompanied by emotional strain, compounding the overall impact on wellbeing.

> ***Disruption, particularly due to having a child with additional needs and needing help to attend extra appointments. Side effects being upsetting and stressful, the uncertainty related to this and additional time needed to recover compared to usual, which added to anxiety.***

4 Barriers and concerns

Patients were asked to reflect on the main challenges they encountered when switching IG products, providing insight into the barriers experienced during this transition. These were grouped into three key areas: practical, educational and emotional. **Understanding these barriers is critical, as they highlight not only the logistical demands of switching, but also the areas where patients may feel most vulnerable or uncertain when adapting to a new product.**

Across responses, barriers to switching were rarely experienced in isolation. Practical challenges related to supplies, scheduling, and physical recovery often intersected with educational uncertainty and emotional anxiety, particularly during the early stages of switching. Patients described how **gaps in information or support could amplify stress and undermine confidence**, reinforcing the importance of viewing barriers as interconnected rather than separate issues.

Practical barriers

1. Managing supplies and deliveries
2. Scheduling infusions around work, family, and daily responsibilities
3. Physical discomfort, fatigue, or recovery time following infusions

Educational barriers

1. Correct administration technique
2. Distinguishing between expected side effects and symptoms requiring clinical review
3. When and how to seek help

Emotional barriers

1. Anxiety around self-administration
2. Fear of “doing something wrong”
3. Feeling overwhelmed during the early stages of switching.

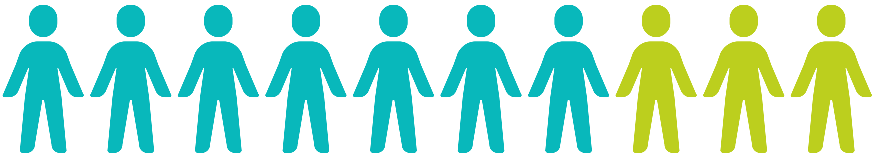
5 Reported outcomes following switching

Patients described a range of experiences following a switch in IG therapy, with responses varying depending on how long they had been established on the new product. In this context, it is helpful to distinguish between satisfaction and confidence. Satisfaction reflects how patients feel about the switch itself and the therapy they are now receiving. Confidence, by contrast, relates to how secure and supported patients feel in managing the new product, including administering treatment and recognising when to seek help. Both are important in shaping trust and the overall experience of switching.

Satisfaction with current therapy increased with time since the most recent switch. **Among patients who had switched in the last six months, around 72% reported being satisfied with their current therapy.** This rose to 82% among those whose switch occurred six to twelve months ago, and around 85% among those who switched over a year ago.

This pattern indicates that satisfaction with the new therapy tends to strengthen over time, as treatment becomes integrated into daily life and patients regain routine and confidence.

Reported experiences were closely linked to how the switch was managed. Patients who reported being informed and involved in the decision to switch were more likely to describe higher levels of satisfaction with the outcome, reinforcing the importance of clear communication and ongoing support, particularly during the early stages following a switch.



Around 7 in 10 patients were satisfied with their therapy within six months of switching

> ***Once I settled into it, it was fine – but the support made the difference.***

> ***I have had to change several times in the past due to side effects. It is important to have a variety of products to be able to switch if this happens.***

> ***Had immediate reaction/severe side effect observed by the nurse. Had to attend hospital and had it administered there again to verify side effects (!!) I was eventually put on a different brand. I was on previous brand for years doing well so no health-related reason.***

5 Reported outcomes following switching

Importantly, **involvement also appeared to influence confidence, with patients who felt informed and included more likely to describe feeling secure and capable in managing their new therapy.**

- **84%** of patients were satisfied with how the switch was handled when involved
- **38%** of patients were satisfied when not involved
- **86%** of patients were satisfied with current therapy when involved

Patients who described clear communication, feeling listened to, and having access to support during the transition period were more likely to report that switching ultimately went well, even where the change was initially challenging. These responses suggest that reassurance and confidence develop over time but are strongly shaped by early support and the quality of interaction with services.

These findings highlight a consistent theme across the survey: **patients' experiences of switching appear to be influenced less by the specific IG product itself and more by the process and support surrounding the change.** Where patients report feeling informed, involved and supported, higher levels of satisfaction with the decision and confidence in managing treatment are more commonly observed.

> ***I was anxious about changing, but I was reassured and felt safe as the first few infusions took place on the immunology unit.***

HCP survey- key findings

1 Role in switching

HCPs consistently reported high levels of involvement in the delivery of IG therapy switches.

In contrast, involvement in earlier system-level decision-making, such as:

- commissioning,
- procurement, or
- organisational decisions to initiate a switch, was more variable.

89% **HCPs are directly involved in discussing and implementing switches in practice**

44% of HCPs described themselves as very involved in switching decsions

Nearly a quarter (24%) reported minimal or no involvement in switching decisons, despite being responsible for delivery

Regardless of their level of involvement in decisions, HCPs reported responsibility for:

- communicating changes to patients,
- coordinating training,
- managing practical and clinical implications,
- and providing reassurance and follow-up support.

This highlights a structural tension in which frontline team absorb much of the operational and emotional workload associated with switching.

In parallel, **14% of patients were mostly or very dissatisfied with how their most recent switch was handled**, suggesting potential misalignment between where decisions are made and where their impact is managed.

“I'm grateful for my care and treatment on the NHS, but this feels forced through, more akin to a vet/animal relationship than a doctor/patient partnership.”

2 Confidence and clinical preparedness

HCP confidence in managing IG therapy switching varied considerably across professional role, experience, and access to training and guidance. Confidence and preparedness were highest among those working in specialist roles, particularly Clinical Nurse Specialists (CNSs) and consultants or doctors. 52% of Clinical Nurse Specialists described themselves as very involved in decisions related to switching, whilst 35% of consultants and doctors also reported relatively higher confidence and involvement in decision-making.

However, confidence was not widespread, even within these specialist groups. 24% of HCPs reported minimal or no involvement in switching decisions, suggesting that preparedness is linked to role proximity to specialist decision-making, rather than being embedded consistently across services. Respondents in smaller or less specialised roles were more likely to report limited involvement and confidence, indicating that access to training and guidance is uneven across professional groups.

Such variations were mirrored further in responses relating to clinical guidance. Among CNSs, fewer than 25% reported that existing guidance was adequate, while a substantial proportion indicated that guidance was either inadequate or only partially sufficient. Consultants and doctors expressed similar concerns, with fewer than 50% reporting access to guidance they felt fully supported effective implementation.

- **52%** of Clinical Nurse Specialists described themselves as very involved in decisions related to switching
- **24%** of HCPs reported minimal or no involvement in switching decisions
- Fewer than **25%** Clinical Nurse Specialists reported that existing guidance was adequate

2 Confidence and clinical preparedness

Where switches involved changes to administration methods, for example between intravenous (IVIG) or subcutaneous (SCIG) uncertainty was more pronounced.

Where switches involved changes to administration methods, for example between intravenous (IVIG) or subcutaneous (SCIG) uncertainty was more pronounced. These modalities differ in setting and practical delivery, such as hospital-based infusion versus home-based administration, and therefore require different training and monitoring approaches. HCPs reported that clinical preparedness in these situations relied heavily on local practice and individual experience rather than standardised pathways. The additional training required was reported to fall disproportionately on nursing teams, often without protected time or additional capacity.

This is occurring within a wider context of workforce constraint across clinical immunology services. National workforce analysis indicates that services are already operating under significant pressure, with rising patient demand and limited workforce growth, and some services covering large populations with minimal staffing[1]. In this setting, the additional requirements associated with implementing therapy switches may further increase pressure on already stretched teams.

> ***Guidance appears to be individual views, not collective.***

> ***As we are the only team who complete training and set up SCIG, we are the ones who have had to make the guidelines.***
>
> ***Clinical Nurse Specialist***

> ***Services are stretched even without multiple switches.***
>
> ***Consultant/Doctor***

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[1] *British Society for Immunology (2025). BSI-CIPN Workforce Report: Moving towards a workforce equipped for the future. [online] Available at: https://www.immunology.org/clinical/bsi-cipn/bsi-cipn-workforce-report-moving-towards-workforce-equipped-future.*

3 Operational and system-level barriers

33% of HCPs rated communication from commissioning bodies as poor or absent

33% of HCPs felt adequate guidance for managing switches does not exist

35% of HCPs reported communication and guidance was mostly clear but not timely

Operational challenges associated with IG therapy switching have intensified over the past year, due to the implementation of the NHS commissioning framework. Limited clinical time was consistently cited as a key barrier, particularly in relation to patient education, training, and managing the increased volume of queries that accompany switching. These pressures were most acute during large-scale or time-limited switching programmes, which many HCPs linked to centrally driven, non-clinical changes.

Responses suggest that switching patients onto different IG products has become a frequent and ongoing component of routine practice. **Nearly three quarters (74%) of HCPs reported supporting IG therapy switches regularly or very frequently**, with almost half (46%) managing switches several times per month. It should be noted that this reflects practice in nations operating under the current commissioning framework. As Wales is not subject to the same national arrangements and switching there remains more commonly clinically driven, patterns of regular switching are not directly comparable across all UK nations.

In addition, **69% of respondents reported that system-level switches were more challenging to deliver than clinically-initiated changes**; with HCPs reflecting on additional coordination, communication, and resource demands associated with implementation. HCPs regularly described switching as being delivered alongside existing clinical responsibilities, often without additional staffing or training capacity.

Communication and coordination emerged as critical pressure points in this environment. HCPs described variability in the clarity and timing of communication from commissioning bodies, affecting their ability to prepare services, staff, and patients adequately. Responses indicate that challenges were driven less by the absence of information alone and more by when and how guidance was received.

3 Operational and system-level barriers

Notably, responses from Wales indicate a different pattern of switching compared with England, Scotland and Northern Ireland. **In Wales, switching was more commonly described as being driven by clinical need, with fewer references to system-level or non-clinical drivers compared to respondents in framework-aligned nations.** Wales-based HCPs reported fewer framework-driven switches and placed greater emphasis on clinical discretion in decision-making. This suggests that differences in commissioning arrangements may influence both the nature of switching and the associated operational burden on services.

> ***Organisation is typically on mass within a set time frame. This has to be done alongside the routine everyday work.***
>
> ***Clinical Nurse Specialist***

> ***We have not had to switch any patients for non-clinical reason in Wales and believe this to be significantly better for the patient, the clinical team and the economy.***
>
> ***Clinical Nurse Specialist***

> ***It is very time consuming to communicate changes, more significant with our very large home therapy cohort.***
>
> ***Clinical Nurse Specialist***

> ***I struggle to see the cost of switching all of these patients to different products is cost effective, I believe it has caused undue pressure on immunology depts. reducing patient care.***
>
> ***Patient***

4 HCP support role for patients

A substantial increase in patient support needs during periods of IG therapy switching was described by HCPs, particularly where changes were perceived by patients as imposed or driven by non-clinical factors. Healthcare professionals play a fundamental role in supporting patients through treatment transitions, acting as a key source of information, reassurance, and continuity of care. **Switching was found to frequently trigger heightened patient anxiety, increased volumes of questions, and concerns relating to safety, and self-administration.**

These support demands were most pronounced in the early stages following a switch, aligning with patient-reported experiences of reduced confidence during transition periods. HCPs noted that patients often sought repeated confirmation that the new product was safe, effective, and comparable to their previous therapy, particularly when explanations were limited or delivered late. **This resulted in increased contact with services, as patients attempted to regain confidence and reassurance.**

This increased need for support occurs alongside existing operational pressures. Many HCPs expressed concern that limited time and resources constrained their ability to provide the level of reassurance, education, and follow-up they felt was necessary to maintain patient confidence and adherence during transitions. In this context, **switching was described as generating not only additional workload, but also a sense of professional discomfort, where staff were aware of patient anxiety but lacked sufficient capacity to address it fully.**

> ***Switching products for non-clinical reasons poses so many difficulties for the patients and clinical staff. Increased pharmacy time, more hospital visits for the patient and staff to perform those visits. Homecare companies have been ill prepared for huge scale of switching we have seen over the last 6 months. We have had to pull nurses off other work to manage the switches within the timescale.***
>
> ***Clinical Nurse Specialist***

> ***When patients are being forced to change product, they approach with many more questions and anxiety around the switch.***
>
> ***Clinical Nurse Specialist***

5 Reported outcomes from the HCP perspective

Despite the operational challenges described, HCPs outlined factors associated with smoother implementation of IG therapy switching. Responses suggest that experiences were strongly influenced by the extent to which the process was planned, communicated and supported.

1 HCPs described smoother switching experiences where decisions were clinically justified or patient-centred, and where the rationale for switching was clear to both staff and patients

Early and transparent communication was repeatedly highlighted as critical, particularly where sufficient lead-in time allowed services to prepare patients, coordinate training, and manage practical arrangements in a planned way. In contrast to large-scale or time-limited organisational switches, respondents noted that switches introduced with adequate notice were easier to integrate into routine care and generated fewer patient concerns.

2 Access to clear, consistent guidance and standardised patient-facing materials was an important factor influencing how switching was delivered

Where HCPs reported receiving timely information and practical resources, they also described greater confidence in implementing switches and fewer issues related to uncertainty or variation in practice. Adequate capacity for training and follow-up was similarly associated with smoother implementation, enabling staff to address patient questions, reinforce understanding, and support confidence during the transition period.

3 Adequate capacity for training and follow-up

Adequate capacity for training and follow-up was similarly associated with smoother implementation, enabling staff to address patient questions, reinforce understanding, and support confidence during the transition period. Beyond initial training, respondents highlighted the importance of ongoing access to support, particularly in the early stages following a switch, where patients may require reassurance or clarification once using the new therapy in practice.

Cross-cutting themes

Taken together, the patient and HCP surveys reveal a set of strongly aligned themes that reinforce the need for improvement in how IG therapy switching is planned, communicated, and supported.

1 Support matters as much as the therapy itself

A consistent theme across responses was that the experience of switching appeared to be influenced less by the specific product and more by the support surrounding the transition. Across both patient and HCP responses, qualitative feedback indicated that **remaining on an existing therapy was generally viewed as preferable where possible.** Switching was commonly described not as a desired change, but as a required or externally driven adjustment, reinforcing the importance of careful communication and support when transitions occur.

Within this context, patients more frequently described favourable experiences when they felt well informed and supported, while HCPs reported that implementation was smoother when patients were given sufficient time and support to adapt. Even where switches were clinically appropriate, limited support structures were associated with more challenging experiences. Conversely, **stronger support arrangements were linked to smoother transitions, fewer reported issues, and higher levels of patient satisfaction and confidence.**

2 System constraints shape experiences

System-level pressures were evident across both surveys, although experienced from different vantage points.

Patients commonly described the downstream effects of system-driven switching, including disruption to established routines, a perceived loss of choice, and emotional strain. HCPs highlighted upstream pressures such as procurement timelines, capacity constraints, and limited notice, shaping how switches were implemented in practice.

Despite these differing perspectives, responses point to the same conclusion: **system-level decisions directly influence individual experience and service burden.**

Cross-cutting themes

3 Confidence and access to information during switching

Patients and HCPs both recognised that **confidence is not immediate but develops gradually over time.** Patients described early stages following a switch as characterised by uncertainty or anxiety, while HCPs acknowledged the need for reassurance and follow-up, particularly soon after initiation.

The limitations of providing information only at the initial stage of switching were also evident. Several patients described receiving guidance or training at the outset but having limited follow-up once managing therapy independently at home. Questions and concerns often emerged later, when patients were administering treatment on their own, sometimes leading to uncertainty or anxiety.

This suggests a **gap between initial instruction and sustained confidence in real-world settings,** particularly for those self-administering. Switching pathways that rely primarily on information delivered at the start may not fully account for evolving questions during the early transition period, potentially increasing subsequent requests for reassurance or support from services.

> ***Patient choice and clinical implications should be the only factor in switching patients. Cost saving and lack of product choice has a negative impact to patients and services.***
>
> ***Clinical Nurse Specialist***

> ***With organisational switches, usually multiple patients have to switch at once, taking up lots of nurse time. Individual switches are fewer, and more spread out.***
>
> ***Consultant/doctor***

> ***Erosion of trust between immunology team and patients. Decisions being made for rather than with patients.***
>
> ***Patient***

Recommendations

1 Ensure every IG switch is grounded in clear, patient-centred communication

Patient responses consistently highlight that satisfaction with the process of **switching is less shaped by the product itself and more by whether patients feel appropriately informed, listened to and supported.** Where communication was perceived as limited, unclear or insufficiently timely, patients were more likely to describe anxiety, reduced confidence and disruption to daily life.

Survey findings demonstrate that switching can carry tangible practical consequences. Many **patients required additional appointments or travel, incurred out-of-pocket costs, or needed to take time off work.** These impacts were often cumulative, disrupting established routines and increasing the time, effort and financial cost associated with managing treatment.

IG therapy switching processes should therefore explicitly prioritise clear, transparent communication and shared decision-making wherever possible. Where switching is system-driven, this should be openly explained, with acknowledgement of patient concerns and clear opportunities for questions and reassurance. Given the measurable impact on patients’ everyday lives, **careful planning, early engagement and practical mitigation of additional burdens should form a core part of any switching approach.**

Recommendations

2 Align national switching decisions with frontline delivery capacity and realities

HCP responses demonstrated that frontline teams carry primary responsibility for implementing IG therapy switches, regardless of where decisions are made. Even where switches are driven by procurement or policy, **HCPs remain responsible for patient communication, training, coordination and reassurance, often within existing time and resource constraints.**

Respondents described additional clinical and administrative workload associated with switching activity, particularly were undertaken at scale. This increase in workload has significant operational implications for immunology services, as staff time, clinic capacity and administrative resources must be absorbed within existing budgets and workforce structures.

System-level planning should more explicitly account for frontline delivery capacity, including the time, administrative resource and clinical input required to implement switches safely and effectively.

This must include earlier communication to services, adequate lead-in time and recognition that education, reassurance and coordination are core components of switching rather than optional extras. **Improving alignment between system decisions and service capacity may reduce operational strain, and support safer, and more sustainable implementation.**

Recommendations

3

IG therapy switching should be a supported transition

Patients described barriers to switching as interconnected, encompassing practical, emotional, informational and system-level challenges. HCPs similarly characterised these pressures in operational terms, including time, staffing and pathway constraints. These joint perspectives highlight that the impacts of IG therapy switching accumulate over time rather than as isolated events.

Patient confidence and understanding was consistently highlighted in responses as something that will develop gradually following a change in IG product, particularly among those self-administering. Early stages were often characterised by uncertainty and anxiety, while HCPs emphasised the importance of follow-up beyond initial training or initiation. These findings indicate that **switching is best understood as a supported transition rather than a single point of change.**

IG therapy switching should therefore be approached as a structured, multi-stage and integrated process. Underpinned by clear and ingoing communication throughout the transition. Pathways should recognise and normalise early uncertainty, ensure information and support remain accessible beyond initiation, and incorporate follow-up that reflects how patients adapt in real-world settings

Embedding communication and review in this way may help mitigate reduced confidence, increased anxiety and additional service demand identified in the survey, while providing a practical means of improving patient experience, supporting frontline staff and strengthening system resilience.

Conclusion

The introduction of the NHS commissioning framework has increased the frequency of IG therapy switching across much of the UK over the past year. A significant proportion of this activity is linked to system-level decision-making, rather than clinical reasons.

The findings of this report indicate that switching associated with commissioning considerations is now a more routine feature of service delivery. While many patients report satisfactory outcomes once established on a new therapy, experiences are strongly shaped by how switches are communicated, planned and supported in practice.

Patients described experiences influenced by limited involvement in decision-making and by the cumulative impact of switching on daily life, particularly where the rationale for change was not clearly explained.

In contrast, where patients felt informed, listened to and adequately supported, they were more likely to describe favourable experiences, even where the initial adjustment was challenging. **Communication, shared understanding and structured follow-up therefore emerged as central determinants of how switching was experienced.** These findings highlight the importance of not only providing information at the point of change, but ensuring that patients feel able to engage with and understand decisions affecting their care over time.

HCPs echoed these themes. Frontline teams described the operational realities of implementing switching programmes within existing workforce and capacity constraints, while retaining responsibility for communication, training and reassurance.

Where planning and communication were clear and timely, transitions were described as more manageable for both patients and services. Where they were limited, switching was associated with increased workload, heightened patient anxiety and additional staff pressure, reinforcing the need for coordinated and well-supported implementation approaches.

Differences across the UK further illustrate how the underlying drivers of switching shape both implementation and experience. Although the Welsh sample was smaller, responses suggest a clearer distinction in motivation, with switching more commonly described as clinically led. Experiences in this context appeared more stable where patients understood the clinical rationale for change.

In contrast, in nations operating under the commissioning framework, where switching was more frequently perceived to be influenced by system-level considerations and where patients reported limited input into decisions, particularly in the absence of adequate communication and follow-up support, the impact was described as more pronounced, including disruption to daily life and reduced confidence.

These findings demonstrate that IG therapy switching cannot be treated as a standalone operational exercise, but rather as a service-level intervention with direct implications for patient wellbeing, workforce capacity and system sustainability.

As commissioning arrangements continue to evolve, national decisions should be accompanied by delivery models that prioritise transparent communication, adequate lead-in time and sustained support. Embedding routine patient feedback and incorporating HCP perspectives into ongoing refinement will be essential to ensuring that future switching is informed by lived experience as well as policy objectives.

These findings highlight an opportunity for the NHS to support a more balanced and sustainable approach to IG therapy management across the system. Ensuring that future decision-making is informed not only by system priorities, but also by the experiences of those directly affected, will be essential to improving both patient and service outcomes.

Appendix

The findings presented in this report reflect the real-world experiences of patients and healthcare professionals navigating the impact of IG therapy switching. These experiences do not exist in isolation; they are part of a broader, ongoing international conversation about how treatment decisions for immunodeficient patients should be made, and by whom, and, critically, whether financial and administrative pressures are displacing clinical judgement in that process.

That conversation is one in which IPOPI, the International Patient Organisation for Primary Immunodeficiencies, has long played a leading role. Founded to represent and advocate for the global community of people living with primary immunodeficiencies (PIDs), IPOPI works across national and international levels to ensure that patients receive safe, appropriate, and individualised care. As the foremost patient-led organisation working in this field, IPOPI brings together patient groups from across the world to give a collective voice to those who depend on immunoglobulin (IG) therapy, in many cases, for life.

The concerns raised by patients and clinicians in this report closely mirror those that IPOPI has been documenting and responding to at an international level. In response to growing evidence that patients in a number of countries were being switched between IG therapies for non-clinical reasons, including cost pressures and procurement decisions, IPOPI developed the position statement reproduced below. It sets out clearly why IG therapies are not interchangeable, why switching for non-clinical reasons poses significant risks to patients, and why shared decision-making between doctor and patient must remain central to any treatment decision. Read alongside the findings of this report, it provides both the scientific grounding and the patient advocacy context that underpin the case for change.

IPOPI POSITION STATEMENT: Access to immunoglobulin therapies for patients living with immunodeficiencies

This statement outlines IPOPI's position on the critical importance of ensuring access to the most appropriate immunoglobulin (Ig) therapy for patients living with immunodeficiencies. This includes primarily patients living with a primary immunodeficiencies (PIDs) and associated conditions but also for certain secondary immunodeficiencies (SIDs). IPOPI emphasises that treatment decisions regarding Ig therapy should always be based on a doctor-patient shared decision-making process. IPOPI is concerned by recent developments in several countries that may restrict access to the most suitable Ig therapy for individual patients or compel PID patients to switch between Ig therapies for non-clinical reasons.

A significant number of immunodeficient patients depend on Ig therapies, which are life-saving biological therapies derived from human plasma. Ig therapy is the most important treatment for a majority of PIDs, as it helps to protect patients against a range of infections and to reduce autoimmune symptoms.

It is used to treat various PIDs, including but not limited to common variable immunodeficiency (CVID), X-linked agammaglobulinaemia (XLA), X-linked hyperimmunoglobulin M (Hyper-IgM) syndrome, Ataxia Telangiectasia (AT), Wiskott-Aldrich syndrome (WAS), severe combined immunodeficiency (SCID) and other combined immunodeficiencies. For these patients, Ig therapy is a life-long, life-saving treatment which must be administered regularly and for which there is no alternative treatment. Ig therapy is also increasingly used to treat patients living with certain SIDs. While some SID patients will require Ig therapy[1] others will not. Ig therapy is primarily used for SID patients with severe antibody failure due to underlying diseases or medical treatments[2]. In some instances, Ig therapy for SID may also only be required on a short-term basis until the immune system recovers.[3]

Ig therapies are not generic medicines. Each Ig therapy is a unique biological medicinal product and as such Ig therapies are not interchangeable. Unlike chemically-based pharmaceuticals, biological medicinal products are composed of an active ingredient derived from a biological source (human plasma in the case of Ig therapies). The active ingredients are isolated using complex processes that will have an impact on the properties of the final product. It is well established that the differences in the processes used to manufacture the products will affect individual patients' tolerability, risk of adverse events, infusion rate, and potential efficacy. Factors such as the volume load, the type and concentration of the excipients used in the preparation, the protein concentration, the osmolarity, the pH and the formulation (liquid or lyophilised) will all affect individual patient's tolerability to a given therapy. [4]

These variations alter the final product and some Ig therapies may cause specific anaphylactic reactions in patients and a personal approach should be taken in order to provide for their specific needs. There are several publications outlining the fact that Ig therapies are not interchangeable and that patients experience adverse reactions when they change from one immunoglobulin product to another.[5,6,7,8,9,10,] In addition, the mode of administration can also have an impact on how well an individual patient will tolerate a particular Ig therapy. Whilst some patients may tolerate an intravenous product but not a subcutaneous product, others may not and vice versa.[11] Calls for individualization of patient treatment in PID highlight the importance of patient input into decision-making when choosing the most appropriate therapy.[10,12]

It should also be noted that the impact of a poorly tolerated Ig therapy will not only affect the patient's health but will bring about significant unnecessary budgetary consequences as the patient will more likely require additional treatments (i.e. antihistamines, extended treatment, hospital visits etc); thus the importance of ensuring patients get the most suitable therapy to their individual conditions and tolerability profile. This also ensures that the patient has a better quality of life, less episodes of ill health and less additional medication.

Importantly, the World Health Organisation has acknowledged the need for patients with PIDs to have continued access to the treatment that is better adapted to their needs and has included immunoglobulins in the List of Essential Medicines for adults[13] and paediatric populations.[14]

Moreover, in a recent meeting of the Wildbad Kreuth III organised by the Council of Europe's European Directorate for the Quality of Medicines & Health Care, with expert nominees from 36 Council of Europe member states, together with representatives from observer countries and regulatory agencies (such as the EMA and FDA) agreed on a consensus statement that recognised, amongst other items, that "Ig products differ from one another[15] ". It has also been recognised that "the efficacy and side effects […] may differ from product to product, and even from batch to batch (e.g. TEE and hemolysis) [15] ". These side effects have been further developed in the medical literature and encompass, amongst others: anaphylactic reactions, thrombosis, aseptic meningitis, stroke, seizure, loss of consciousness, and acute respiratory distress syndrome.[16]

IPOPI strongly recommends that necessary measures should be taken at national level to ensure PID patients can have continuous and equal access to the Ig therapy that suits them best. Hospitals, pharmacists, health insurances should provide the widest range possible of safe effective Ig therapies, for both intravenous and subcutaneous administration routes, including also a choice in dosage and concentration. Access to Ig therapies for PID patients, including the selection of the most appropriate Ig therapy for an individual patient, should always be achieved through a doctor-patient shared decision-making process and not dictated by financial considerations. Prescribing physicians and other healthcare professionals should always have the flexibility to choose the most appropriate therapy for their patients.

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