IMMUNO DEFICIENCY UK

Supporting families affected by primary and secondary immunodeficiency

Patient and healthcare professional experiences of switching immunoglobulin (IG) therapy products

Free text responses and analysis

This appendix to our main report provides further in-depth analysis of the realities of switching IG products from patients and healthcare professionals.

June 2026

Immunodeficiency UK is extremely grateful to patients and healthcare professionals who provided rich insights into their views on IG commissioning, and the impact and challenges they face when switching of IG products is mandated.

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Analysis was performed using Microsoft Copilot 365 using automated coding systems to define key themes and sentiment.

Patient free-text responses

Theme: Patient's understanding of why the switch was happening and patient choice

"I was told by the day unit that they had heard I was switching but the hospital that oversee my care never got in touch. In the end I had to call them as i didn't feel like I had been given a reason or explanation or option in the decision. This is the third time since 2020 I have had to switch."

"The hospital decided to switch my product. I found out when I arrived for my next treatment. They would be using a UK product and I started immediately."

"Because it was a dictated switch of product made by the NHS rather than the clinical team treating me."

"Decision should be part of overall care."

"The decision had already been made by the NHS who source my treatment. I had no input in the decision making."

"It was a directive, the product was scarce, so I had to switch to one that was available."

"Due to the immunoglobulin not being made anymore I had to switch."

"The brand to which I was switched was selected for me. There was no discussion whether it's a good fit. I was informed that I would be switched and was retrained with a new method to be able to self-administer at home."

"There was no choice - my child was told that the product would be switched and that prefilled syringes would no longer be available. It was a fait-accompli."

"Actually, I begged the Dr. for the change. I could do it myself."

"Discussed with consultant and CNS and considered what would, be most suitable and most similar to previous IVIG brand and product content."

"This government doesn't care about us, we are being given the very least, and cheapest drug available."

"Hospital just said we had to switch products - in think the previous contract had run out and new one was cheaper."

"I was just told this is what they are using now."

"It just happened."

"I've personally followed the change from non-UK serum to the recent decision and am happy with it."
"It was going to happen unless I had a good reason."

"It was discussed with me, and I had the option to change or not."

“[named IG product] wasn’t going to be available anymore so I needed to move to another SCIG, so I moved to [named IG product].”

“No discussion. I was informed [named IG product] was apparently no longer an option. I was led to believe it was a cost option. Having said that I am now having [named IG product] which is cost effective and is Uk produced.”

“Because I didn't have a choice. Decision made by NHS.”

“I've never been told why it has to happen. I infuse at home and having to travel to hospital and stay for some time is not ideal.”

“I was told it was now being used as a product produced in the UK rather than an imported product.”

“I was told switching is compulsory but not driven by the [named hospital] but the NHS to reduce costs.”

“It’s obviously to do with NHS commission changes. And I imagine cost and availability.”

“I was offered options.”

“It was discussed with me for the side effects.”

“I was told it was NHS rules.”

“I feel well looked after and in good hands. It has been explained that the change will be minor- a different product. A change after a re-tendering exercise.”

“I was sent a generic letter saying that I would have to switch my therapy to and listed some new therapies. I was not told which therapy I could change to so I was unable to research the possible options. In the letter it stated that the reason behind the change was due to new contracts being offered to alternative suppliers and that due to recent shortages of IVIG products it would be advantageous to use a supply developed and supplied in the UK. I was offered an alternative by my consultant [named IG product] as it was manufactured by the same company as my present [named IG product]. I said I was not happy to change product as I have been on it for forty years but I would consider it if I have to. I researched [named IG product] and found out it was manufactured in USA and from paid donors. This contradicts the reason for changing products to a UK supplier. After the 80s I am reluctant to consider this option. Since then, I have informed the immunology team that I do not want to swap. I said I had not been given any information about the other products and which product I would potentially swap to. I said this is not informed consent and I needed more information in order to do so. I was told I could speak to the pharmacist which I agreed to. I am still waiting for a call. I still have no idea as to which product I would have to change to. I was told I could either buy [named IG product] privately or go without treatment and this was confirmed by yourselves. Hardly a choice! Having infusions every week with the same product for forty years I think is a very good reason for not swapping as it is still available .I would have to have the first two infusions in hospital in case of any reactions which I think is an unnecessary risk and probably costs more for the hospital ward and nurses time than any savings the NHS may get changing to a cheaper product. I have spoken four times to the immunology nurses, but I am still none the wiser for it. I have found this very upsetting and I am still in the dark not knowing what will happen. I was told by one of the nurses that my case had been put in front of a committee and that the answer was no to changing products. I think this has been badly handled and feel as a patient I have no voice.”

"Just had a letter stating problems with supply and the hospital was working closely with NHS to identify an alternative. Sorry to be asked to change products again, all beyond hospital control and just accept apologies, letter came from consultants for Immunology. “

“I was just told that my immunoglobulin was being changed no reason was given to me although i have since been told that the product I was getting was a re-brand due to being produced from entirely UK donations now. It was [named IG product] and now its [named IG product].”

“I was told that I would have to switch as they could no longer get [named IG product].”

“The product was unavailable.”

“Because the product I was using was no longer going to be available.”

“I was informed that the switch was going to take place, and that it would be better because it used British blood donors, with less risk of infected blood in the donor pool. I had no objection to the change.”

“I was told that I would be changing to [named IG product]. The NHS had a better price for this product.”

“Advised that my product was no longer available to due NHS procurement tender which meant that the NHS would no longer be buying [named IG product].”

“It was the hospital/consultant choice to switch from [named IG product] to [named IG product] 3 weeks ago.”

“I received a letter informing me about the switch. No choice. Believe it was due to previous product not being chosen by health board/ budget reasons.”

“I was informed there was a shortage of my product, I understand this and am very laid back so it had to happen.”

“I was told the switch was being made and to which brand, but I wasn’t asked if I wanted to change, or if I was happy to change.”

“No discussion- didn’t even know name of product to be switched to. Have since had a further switch due to complications.”

“It was communicated as a fait accompli. However, the timing of the switch was a negotiation between me and my (supervising) immunology centre/clinic.”

“Very poorly communicated and had no choice or discussion.”

“Wasn't given any options.”

“I was told that this was what's happening no real choice in the process.”

“I wasn't consulted I was just told. You'll be on different treatment after your current supply runs out.”

“We were told the switch was happening.”

“NHS England were no longer funding the product [named IG product].”

Analysis

The responses were mainly negative (75–80%). The key themes were:

1. **Lack of choice -** felt decisions were predetermined and imposed.

2. **Poor communication -** late, unclear, or incomplete information with no opportunity to ask questions. Generic letters were sent with missing details.
3. **System-driven decisions -** switches perceived as NHS-led, not clinician-led.

About 10–15% of respondents accepted the supply issues and the changes involved.

A small minority (5-10%) reported positive, collaborative experiences, showing that good practice is possible but inconsistent. A positive experience was gained through discussions with the clinician, options being offered, side effects explained, and a clear rationale provided.

Patients' expectations include

- ✓ Clear explanations
- ✓ Named product information
- ✓ Shared decision-making
- ✓ Safety and origin details
- ✓ Respect for long-term treatment stability
- ✓ Advance notice of the change

Theme: patient experience & feelings about the decision

"Eliminated allergic reaction."

"Because they asked if I was open to the switch and explained the reasons. Plus, I was already aware from reading literature on your website and emails I had received outside of the NHS."

"I had been having problems with the apparatus that I had previously been using and this change was offered as an alternative."

"[named IG product] stock was running out, there's not much choice when stock is low, you just have to get on with it."

"I was informed the swap was immediate and the new product would be delivered."

"Based on side effects I experienced."

"From the letter I received it was clear that my current product would no longer be available to me unless I was unable to tolerate the new suggested product or alternatives."

"The brand was changing and I was then required to go into the hospital for several treatments due to the home delivery taking a long time to arrange. It didn't seem like not swapping was an option."

"When I was told that I was being switched to a different brand the decision had already been made. I had no choice to say in the original product."

"I was told they needed to switch my product. I asked if I could stay on the same one ([named IG product]) as I had had reactions to other brands in the past ([named IG product]). I was told that there was no choice but to switch to [named IG product] unless I reacted to it."

"I knew that it was likely to happen due to reading about the licencing changes but didn't have any advance warning. It happened because [named IG product] is no longer approved for NHS use."

"Due to availability issues I didn't have much say in the switch but did in the options after. What product next, stick to IV or switch to subcut etc."

"I had an unfounded fear that it would not work as good. And didn't want to change brands."

"I requested the change because of how extreme the side effects were. The switch itself took far too long, resulted in me being hospitalised with aseptic meningitis which was dismissed by my consultant."

"It was to do with the product being available and going out of circulation for us to have to switch."

"Was not discussed at all with me, was given no choice and heavily affected my heath."

"They just said I had to switch product."

"I requested the switch."

"Was thoroughly discussed but was only option left for me."

"It was an NHS decision."

"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."
"The Product I was receiving was no longer available."

"It was discussed with me several months before the actual change over. It seemed like a sensible decision given financial and security of supply considerations."

"Product switch mandated by NHS policy."

"I was happy to switch as the new IG was better."

"One month it was 1 product the next month it was a new one."

"I was informed by my supplier that my product was changing. I had no letter or contact from the hospital informing me of a change. When chased by myself they admitted I had been missed. Last minute appointments were made for the change to take place."

"We were just informed that the brand was being changed we were not involved or asked for our opinions."

"[named IG product] was not on NHS England list anymore."

"It was explained to me that the switch had to be made as the NHS had changed the supplier of the medication."

"Already decided unless a severe reaction happened!"

"Decision was made without consultation."

"I didn't have the option to switch. However, if there had been problems, then I would revert to the original product. The first administration was done in hospital with the specialist nurse, both as a training for me on the new product and to ensure that there were no unexpected side effects."

"Had to change product several times in last few years due to supply issues. On two occasions turned up at Hospital and there were no supplies and had to return or transfer to an immunology centre."

“The switch was made at the start of covid when neither patients nor staff had any option but to isolate where possible.”

“I was told it had to happen and the new brand was chosen for me based on availability.”

"I was consulted due to negative side effects I was experiencing with previous medication."

"My original product was being withdrawn and the new product was a match for my need."

"My product was discontinued."

"I just received a letter to inform me of the change and when it would be done."

"I have a very good relationship with the team at the hospital who administer my IG and feel that any changes are as a result of informed discussions."

"Was fully discussed with me."

"It was simply a fate accomplished, I was told I had to change as there would be no more [named IG product], I thought they were moving to UK supply as opposed to USA but in fact my product is not UK."

"Advised by Consultant prescription was being changed."

"I was told I would be changing product type and it was explained why this was happening. I was not offered a choice."

"Because I was told it would happen. No explanation as to why."

"There was no choice as [named IG product] is no longer an option."

"I was told NHS was switching from [named IG product] to [named IG product] (both SCIg products) for financial reasons. This appeared to be a UK-wide decision. I was assured that the formulation of the two products were pretty much identical and therefore there was not expected to be any noticeable difference between the two. For me, this has turned out to be true."

"It related to a contract change so I don’t think I could have refused."

"IV delivery increasingly problematic with vein access. Additionally, I had a suspected adverse reaction to the IV IGG and it was felt it would be better to switch to a subcutaneous option."

"This was fully discussed with me with both haematology and immunology consultants."

"I was using [named IG product], and I was told the government were no longer going fund it, I had no say in it."

"[named IG product] had lost the contract so I had to switch. Immunology Nurses were great with communication [named centre]."

"The brand I had been using is no longer available."

"I was on intravenous and wanted to try subcutaneous."

"It was an NHS funding decision."

"The reason for switching was to use UK based supply panel which should guarantee supply availability now that we have left the EU. The volume of product I needed to infuse and the method of delivery was exactly the same."

"The [named IG product] was changed to [named IG product] by the manufacturer, so no choice was available. But it has meant a quicker infusion time, and no side-effects."

"I was told it was happening from a U.S supplier to U.K. one. On reflection I blindly accepted it."

"I was told the medication I was on was no longer available as the company had not put in a tender to the NHS."

"I was just told I had to switch."

"I wasn't included in any discussions, I was just told the change was taking place."

"Said moving everyone over but unless severe reaction cannot change back."

"I was just advised that the switch would be made and I also received a letter explaining that the NHS had reviewed IG suppliers. My preferred supplier was no longer on the list."

"No option as previous IvIg unavailable."

"[named IG product] no longer available."

"I was told [named IG product] was no longer available and I had to switch."

"Found out on the day of treatment the brand had changed."

"Brand was being discontinued."

"I was on daily push and we looked at doing this with the new medication, but it wasn't really an option."

"It was NHS policy. [named IG product] wasn't going to be available anymore due to cost and possibly availability. [named IG product] was said to be similar and made with British plasma for the first time. Which made me feel like it was a bit of a win. But it wasn't really a choice."

"Was told that the NHS would no longer provide my current brand"

"I got a call (at the weekend so I assume they forgot) from pharmacy and [named hospital] telling me they had done a procurement exercise and it was for cost effective and British. I actually knew the change was coming through your newsletter so thank you. My first infusion was 2 days later. It did not go well - like the first ever infusion feeling which was 12 years ago. At next infusion I was offered paracetamol and/or antihistamine as feedback was people were struggling to adapt. I was offered every visit since. It has taken 6 months to adapt and I take a paracetamol at home first now. The irony is when we changed brands briefly in the past (availability issues) we were checked first. This time the pharmacy insisted it was fine. I do not think the nurses or the consultants were checked with first. In short, it was to save money and was poorly communicated with patients. It is hard to comprehend that changing a brand that need a cooler storage (I assume for shelf life) and pharmacy did not think the temperate change would affect patents."

"The product was changed as the previous product became obsolete."

"Hospital advised they were changing supplier and my prescription would be changed."

"It's fine but wasn't a choice."

"It was cheaper, and I was pretty much told by my nurse specialist that I was changing."

"I was told that my medication was changing and was given two options to choose from for the new medication."

"It wasn’t discussed other than a letter telling me my current brand was being discontinued."

"The switch was due to NHS procurement policies."

"Wasn't given any options."

"As [named IG product] was being stopped on the NHS."

"I had no option I was informed of the change."

"Had no choice as product I had been using for years was no longer available, but I was not involved at all - not even the name of the new product until I asked, just given a date to attend the changeover. This first change was in May but I have since changed again - about 5 weeks ago - due to developing hard grape sized nodules at the site of each injection, said they might be areas of scar tissue but haven’t seen a consultant and only had the most perfunctory examination by a nurse. Told to try and use a new area to test this second product but it’s difficult as I have so many of the hard and some tender nodules."

"[named IG product] was suggested even before [named IG product] was withdrawn. I opted for 4 weekly infusions to make life easier."

"Told it was happening rather than asked."

"I was told my previous brand was not available anymore."

"I was told that it was going to happen whether or not I agreed."

"Easy transition. Fully informed."

"At no time was I asked if I wished to stay on my current medication, I was told I was going to be switched and would need to attend for training."

"We were told it was change of contracts within the NHS so would be happening. My son would only remain in his usual brand if he had a reaction to the new one."

"It was a procurement issue."

"The product was no longer available to me."

"I was on [named IG product] and as [named IG product] was not on the new contract I had to change to [named IG product] I was happy with the explanation of product switching."

"I was just told it was changing and using people from uk like they used to before Creutzfeld Jacob disease was an issue."

"I was told about the switch that [named IG product] contract was over and the new brand would be [named IG product]."

"Changes in policy to do with funding and availability of products meant that I needed to change to a different immunoglobulin product."

"Told that NHS had lost the contract and needed to change to an alternative product after 20+ years."

"I was just told that I wouldn't be able to do IV anymore and told to come into hospital (in 2021, when COVID cases were quite high) to receive training in Subcutaneous infusions."

"Policy change to UK manufacturer."

"They stopped manufacturing my medication so had to switch. Tried several before finding one without additional side effects."

"[named IG product] was no longer going to be available."

"Discussed with my immunologist why the change of treatment was necessary."

"I was told the NHS were no longer funding the product."

"The nurses were very supportive."

"The hospital changed suppliers and ancillary products."

"Pharmacy called to say they were switching brand, as it had been switched before and to a previous brand I had used before. Last switch after COVID due to availability."

"They didn’t make my product what I infused at home on a IV version."

"We were just told that there was no other way."

"I understood it was re supply issue."

"Was not an issue for me, my hospital told me the existing product would not be available going forward."

"I was told I had to change brands."

"I had started having a skin reaction, it was discussed using antihistamines which worked but we agreed in the end that was not ideal long term as they had side effects too."

"Because previous brand was no longer going to be available."

"The immunologist had no input it was a decision made by NHS."

"I did not have a choice to stay put as [named IG product] was no longer going to be available but I was able to choose between the 3 brands now made available."

"The different treatment was discussed and the benefits. Also training was given."

"Bad side effects so needed alternative."

"I had a conversation with the hospital initiated by them. They answered my questions and I was happy to switch based on their advice. I did not ask about cost, NHS doctors don't discuss that in my experience, but we did talk about security of supply, which is an issue since we left the EU. I also asked about prions, because the previous product did not come from panels in the UK or France for that reason. They were reassuring about that."

"I discussed side effects with my consultant and he suggested the product was changed. It would have been changed anyway by the end of the year as it had been removed from the approved list."

"This was an NHS policy change which in principle I support. I did feel I had good support from my healthcare professionals although as this was a policy change it obviously wasn't open to discussion."

"Just informed."

"I asked if there was an option to not switch and i was told it was out of my hands."

"My old IVIG is no longer available under the NHS so I had to switch products."

"At no point where any other options discussed, I was not asked for my input."

"I was told it was due to supplier issues and that there was nothing I could do about it."

"I was just told that I would be switching product to NHS changes on the products supplied."

"I was told that [named IG product] was no longer going to be manufactured."

"I was not given any choice."

"Because had used previous immunoglobulin [named IG product] without any problems or side effect."

"Switch was happening no matter what."

"I believe the NHS needed to source a product for monetary reasons."

"Would of been nice to have had a talk with the doctor."

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

"The switch from [named IG product] to [named IG product] was made and I was only informed on the day. I had to request information from the available registrar in the unit."

"Previous IG wasn’t going to be available."

"I was happy with the decision so not going along with it would have been counterproductive."

"The NHS strategy was to switch patients to [named IG product] for supply reasons and the fact that it was made from UK plasma."

"I was told the NHS was no longer supporting my old product, so it needed to change."

"I believe it was a national change in brand use."

Analysis

A summary of patient experience

Experience type	Characteristics	Sentiment
Imposed change	No choice, minimal consultation	Strongly negative

Informed but no choice	Explanation provided, decision fixed	Mixed/neutral
Collaborative decision	Discussion, options offered	Positive
Patient-led change	Patient requests switch	Very positive

Themes were:

1. **Lack of choice / perceived coercion** was a very dominant sentiment. The strongest emotional theme is loss of autonomy.
2. **Limited or poor communication** with gaps amplifying negative perceptions, even when a rationale for the switch exists.

Actions to improve patient experience:

- ✓ Involve patients early, even if the choice is limited
- ✓ Offer some degree of choice where possible (e.g., between alternatives)
- ✓ Provide clear rationale (supply, safety, equivalence)
- ✓ Ensure consistent, proactive communication
- ✓ Support transition (training, monitoring, follow-up)
- ✓ Acknowledge patient concerns and prior experiences.

Theme: the impact of switching

“The switch was a one-time thing and my reaction was a severe hereditary angioedema swell.”

“Required more needle sites and longer infusion time.”

“Had side effects I didn’t have before.”

“I was told about the switch. Tried a different product. Had more side effects. Now awaiting appeal outcome.”

“The first 2 brands I tried had to be discontinued due to side effects. I’ve started a third brand which is going okay but I have been assured by the hospital if this one doesn’t work out, they will appeal to the NHS for me to continue with [named IG product]. The hospital have been entirely supportive.”

“I had suffered 3 episodes of Aseptic meningitis because of IgG brands. It was discussed with my immunology team at decided I should revert to SCIG in small doses of a different brand to avoid further issues.”

“It caused anxiety as was unsure about potential reactions or complications from a new product.”

“Only my anxiety about changing, but I was reassured and felt safe as the first few infusions took place on the immunology unit. I felt safe throughout the whole switch.”

“I had to the first switch in the hospital in case of a reaction before being allowed to continue at home and self-administer.”

“The replacement does not need refrigeration.”

“Impacts were a one-off. My child had to have the first infusion with the new product in hospital to ensure there were no problems.”

“I took a very bad reaction to my new immunoglobulin (eczema all over and lost my fingernails and hair fell out) my body did not react to it well.”

“Bottle size changed, so was more complicated had to go by grams as well as ml so now 10g one week and 6g the next still using 20ml syringe so takes longer as need 3 on one week and 2 the next which need to be filled to 18ml each and not 20ml, needless to say I sometimes got a bit muddled. Also have more side effects in the way of more swelling and feeling more sleepy.”

“Anxiety due to me reacting to 2 new brands. I have a history of severe headache with subcut and IVIG in general”

“Switching brands gives me headaches, body malaise, nausea, and significantly increases fatigue and extends the recovery period.”

“Only just slowing the infusion rate and having more obs for the first four or five treatments with the new IVIG.”

“1st treatment with new product took 3x as long (in clinic). Not sure why.”

“Personally I am able to do these things without assistance or guidance, my instructions were clear, so no problem”

“Nausea.”

“A batch was change due to severe reaction but product remained the same.”

“Not as effective.”

“Very long appointments to retrain and wait till infusion finishes in hospital. As always, any visit to the hospital is a risk to my health due to PID. So it’s always a lot of additional stress and anxiety.”

“Had to sign a new consent form (administrative impact).”

“More freedom at home and fewer sites.”

“Extra appointments needed as had to do the 1st few in hospital – but then they didn’t order the product in time for home delivery and so had to do a 3rd session in hospital when should have been able to do at home at this point.”

“Be nice to know if I had a choice as I would have stuck to the original. This has to be given slower.”

“Worry about having a reaction to the new drug. Pain as the new drug causes more swelling at infusion sites.”

“Asked to attend clinic for the switch of product.”

“I had to administer first dose in hospital under supervision.”

“There is a fault with the bottles/drawing up of the liquid into the syringe. I’ve been doing this 20 years and I can’t do this easily. There is too much pressure/vacuum and the liquid won’t flow. It takes me longer to draw up than for the treatment itself.”

“Side effects of new treatment are approved – overall care by nurses fantastic. Consultant not at all involved or interested in my care.”

“Longer appointments, feeling unwell, having to have someone collect me. Look after children etc as I was in hospital for longer.”

“I suffer with side effects as it is and it took several doses for my body to get used to it. I really struggled for a few months.”

“No: the new product seems to be working well. (incidentally, I have been on gammaglobulin therapy for over 60 years and have been administering it at home since 1987. I was diagnosed in 1964 and must be among the earliest to have been diagnosed. I have always had a good experience at all the hospitals I have been to.”

“Mental load, anxiety – blocked additional time off as concerned I may have a reaction.”

“Had to travel over 100 miles twice, impacted health as new IVIG did not work for me.”

“Had to have pre-meds treatment took a lot longer.”

“Making extra room in my tiny bungalow for all the paraphernalia that SCIG requires.”

“Husband had to have time off work for appointments.”

“Had a reaction to the product so had to keep going into hospital.”

“Suffered severe adverse reaction requiring emergency hospital admission and 4-day stay.”

“I had to phone [named home delivery company) to make sure they were aware of the change. The change of prescription all went through smoothly.”

“My consultant says the new brand is cheaper and will be more available to others”

“New product results in me feeling very very tired on afternoon and evening of infusion.”

“Usually switches have changed under hospital conditions. I watched a YouTube video to work out how exactly to do the change of subcutaneous delivery and then just did it at home!”

“Erosion of trust between immunology team and patients. Decisions being made for rather than with patients.”

“Additional blood tests before the switch.”

“There were no additional impacts, they were just different because of the extra-ordinary circumstances affecting the whole population. I just did my bit to help.”

“I have felt more tired after infusions on the new brand and have needed some time off work as a result.”

“Impacted initial deliveries of medication and associated products during the switchover.”

“It was very frightening, changing to a new product with very little guidance or support.”

“It was very inconvenient, meant a half day in hospital, I find both traumatic and risky as well.”

“I have had to change the day that I go the hospital. This was so that a specialist nurse could monitor me on the new product. After a few sessions I will be able to go back to my normal day. This is not a problem for me but could be for some people.”

“I don’t think I’ve had side effects other than feeling increased fatigue. I’m not sure whether it is pure coincidence but my levels are lower than normal meaning an additional treatment and more product for the next 3 months.”

“Back to slow infusion rates, premeds and longer appointments therefore higher car parking costs.”

“I reacted badly to a previous drug that was infused, I was very worried I would react to this new one.”

“It takes longer as the medication is more diluted, so a larger amount of liquid has to be injected.”

“It made my life immensely better.”

“More itching with new product.”

“The new IG product needs to be refrigerated, so this has obviously had an impact on storage and also affects my travel plans/work commitments on an ongoing basis because it’s more difficult to travel with a product that needs to be kept cold.”

“Emotional stress, anxiety and time chasing information for where to go etc”

“Horrid side effects, brand has had to be changed 4 times.”

“Switch in my delivery type. Daily push to weekly”

“Taxi fares. But that was mentioned already. Possibly could have asked for hospital transport. But that’s not straight forward. And means you have to wait around a lot.”

“Also I felt it meant reorganising a lot for something that was already going so well and had been for many years!”

“Switching from IV to subcutaneous entailed (in theory) a set number of visits to hospital for “training” and sign off. This was poorly managed and communication wasn’t good. In the end I had to refuse to attend additional hospital sessions. Also, hospitals generally give no consideration to the patients journey times, parking difficulties and cost. In my case I had a c200 mile round trip per visit and overall a c9 hour commitment.”

“However, still grateful 🙏 for what I can get.”

“What I wrote earlier: I got a call (at the weekend so I assume they forgot) from pharmacy at Norfolk and [named hospital] telling me they had done a procurement exercise and it was for cost effective and British. I actually knew the change was coming through your newsletter so thank you. My first infusion was 2 days later. It did not go well – like the first ever infusion feeling which was 12 years ago. At next infusion I was offered paracetamol and/or antihistamine as feedback was people were struggling to adapt. I was offered every visit since. It has taken 6 months to adapt and I take a paracetamol at home first now. The irony is when we changed brands briefly in the past (availability issues) we were checked first. This time the pharmacy insisted it was fine. I do not thing the nurses or the consultants were checked with first. In short it was to save money and was poorly communicated with patients. It is hard to comprehend that changing a brand that need a cooler storage (I assume for shelf life) and pharmacy did not think the temperate change would affect patents!”

“Delay with supply of the next infusion”

“This brand is more lumpy (side effect). I self-administer subcut at home. The lumps take a couple of months to go down sometimes.”

“Periods of ill health as my body adjusted to the new medication (about 3 days after each infusion for the first 6 weeks)”

“Anxiety.. took a while to switch over. A lot of confusion over the date of switch. I had to call every 3 weeks to see if it was regular or new brand before attending.”

“The new product didn’t agree with me and gave me terrible side effects. I had to write of two days weekly after every infusion as it made me feel quite unwell.”

“It does not come in pre-filled syringes anymore.”

“Have been advised that there is only one other product available for me, which I have had in the past and had bad reaction too. I had zero information from the hospital and found it out for myself. Lack of support and interest by consultants/nurses has been very stressful as any emails/ queries now go through “admin” so no idea who is going to respond or when. Ringing the Day Unit is an answerphone only option but responses are usually quite quick. It’s been very unsatisfactory in terms of support/information as I live a considerable distance from the hospital I attend. I can well understand why people are reluctant to do home therapy- I met a number who refused when I attended as a day case, but I do not have any other option.”

“Inconvenient and there are side effects if it goes through too quickly, i.e. it takes longer.”

“Difficulty getting the new brand from our usual supplier. We had to do a lot of chasing between the hospital teams, the pharmacy at [named company] and the [named company] delivery team as there was issues and a delay with the new prescription. This caused a lot of worry as we had used our old supply up at home, and my son’s infusion was nearly due.”

“I’ve come off premeds.”

“Additional help with childcare and lifts.”

“Unexpected side effects, anxiety that there wasn’t another one that would work for me. Expenses for dog care travel etc whilst testing up in London.”

“New immunoglobulin has to be refrigerated so when we recently had a 5-hour power cut, we took the product in cooler bags to health centre. They were brilliant and put it all in their fridge until we were back to normal.”

“No other impact and the extra appointment was tied in with technique review.”

“Fear.”

“Slower infusion rate.”

“Required a tester session/dose.”

“Caused me some anxiety, when I first started on the product I had been using, I had some side effects so was nervous this would happen again.”

“I initially had issues with the clinical delivery firm getting my new prescription correct and the correct ancillaries.”

“Refrigeration of medication.”

“Storage changed from ambient to chilled, not an absolute requirement but I felt uneasy returning product to room temperature when it was delivered chilled.”

“I don’t like having to use my fridge to store 10-week supply, it takes up a lot of space.”

“Admin for receiving the new product was not good. Provider was late.”

“Just the ‘not knowing’ being forgotten in terms of being told before it happened and not understanding why.”

“Additional time with using new supplier moved from pre-filled syringe to vial which takes much longer.”

“I had to travel long distance to hospital twice for them to witness me taking my new treatment in case I reacted to the new medication.”

“It has cost me 2 trips to London from Brighton to collect different brands.”

“I have come down with a respiratory infection which I probably caught from travelling on public transport.”

“None – my additional appointment was so I could infuse in clinic the first time I had the product”

“Definitely experience more side effects on [named IG product] however I do prefer the control of administering myself. Also freeing up NHS clinics for more chemotherapy at my local hospital. However, I have been told that my current immunology department have had their staff cut by half. So now only 3 consultants for a very large area and only 2 nurses for over 200 patients.”

Analysis

Positive responses (approximately 13%) were reported. These included greater independence by home treatment, fewer infusion sites and improved convenience. These indicated that the new product was better suited to an individual’s needs and that the transition was well-supported.

However, the dominant experience was negative (65% - 70%) to mixed (20% - 25%), with positive experiences concentrated on convenience or improved flexibility.

Key themes reported at a high frequency were:

1. **Adverse effects & tolerability**. Reports included headaches, nausea, and fatigue; infusion site swelling/lumps, skin reactions (eczema, itching), severe systemic reactions (including hospitalisation), and extended recovery periods. Some patients require weeks to months to stabilise on a new product.
2. **Anxiety, fear & emotional burden.** This included uncertainty about reactions, the impact of past negative experiences and the lack of perceived control due to forced/non-consensual switching. Anxiety persists even when no adverse effect occurs.
3. **Increased treatment burden** from longer infusions and extra preparation, especially when patients switched from pre-filled syringes to vials. The added complexity caused confusion, increased dosing error risk, and reduced independence for some.
4. **Need for hospital visits & healthcare system burden** with switches frequently shifting care from home to hospital temporarily. Switching required mandatory supervised first doses, needing extra appointments and retraining. There was a burden on patients to travel to the clinic, including some reporting having to travel long distances. This was especially problematic for those with childcare/work responsibilities. Some people expressed concerns about the infection risk of visiting hospitals.
5. **Financial & social impact,** including travel costs (taxi, parking) and time off work.
6. **Practical & logistical challenges**, including delivery delays and supply problems, changes in storage requirements, especially refrigeration.
7. **Perceived reduced effectiveness** was reported with moderate frequency. Some patients perceive a loss of disease control even when not clinically confirmed, which impacts their confidence.

Theme: the impact of the switch on mental health or emotional well-being

"Stress and worry whether the new drug was going to be compatible with me or cause allergic reactions with no other drug available to me."

"Anxiety issues. During lockdown there were shortages and I had a couple of unpleasant experiences with other brands. I was concerned that I might experience those again with a new one."

"I was already in hospital and immunologist explained it all...trust we had built over the years, for me the new product caused anaphylaxis. Terrified! I was pre-treated and every precaution followed. I was given treatment but I was very ill and also my mental health which was/is fractured, became heightened… fear was constant ..fear it'd happen again, fear id no longer get ivig, which up to now has prevented multiple infections of every type. Not fully still get but not as many… I then had to trust again… I was drip fed test amounts.. now having full amount.. Thankful, yes, was change on this scale necessary? I don't know! Mental health, shot to pieces…"

"I have used the same product for ~10 years and it works well for me. I'm worried how things will change when I switch."

"I am concerned about any reactions to the new infusion medication beings I have been on [named IG product] since starting replacement therapy. Is there any option of staying on [named IG product]?"

"The change has made me feel anxious and I feel I have minor side effects after infusing now that I didn't have previously. The therapy weighs down on me now whereas I felt fairly relaxed about it previously."

"The treatment I'm on at the moment is working well and I fear the new treatment won't work as well."

"My clinic does not have a specialist nurse so when one called me to discuss, she came in with ideas that were not suitable for me. I don't know if the switch can even be done as I'm told they can't do it at my clinic due to having no nurse."

"I started my treatment ivig just switching back after 20 plus years scig everything explained well when the switch was discussed."

"I think it's because I don't know it will be as effective or if it will have more side effects."

"Being moved from children care to adults so not getting enough information now."

"Explained why, when, and the process for it happening prior to an appointment being made."

"From SCIG (home) to IVIG (hospital)."

"As previous answer anxiety."

"I am independent!"

"I had my old drug [named IG product] for over 20 years, it was one of the few immunoglobins I could tolerate, to find out it was changing, and have no alternative really stressed me. I didn't sleep and felt ill with worry when I found out."

"It's not the hospitals fault, it's a government decision, just like the Covid strategies, these decisions need to include people who understand the people affected."

"I switched to [named IG product] initially and it made me feel exhausted and wasn't able to work so we changed again to try [named IG product] which worked better."

"Curtailment of independence because of lack of prefilled syringes. It is a serious backward step for a young person trying to live independently."

"The impact the reaction had on me was awful and my health care professionals weren't sympathetic to it at all."

"Just felt a bit muddled with it all and taking longer, slightly more side effects."

"I was worried at first just in case it wasn’t as good as the previous one."

"Anxiety as detailed earlier."

"You dread changes because you know they will be a rough and unnecessary transition."

"It's stressful to change to a new IG product, when you are perfectly happy and have no issues with your current treatment. I feel that my previous IG product suited me better."

"It will shortly take place at home. Training is still ongoing, at 74 it's remembering the different procedures."

"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."

"Previous methods with the equipment would often occur faults and then take much longer to administer the medication. Possibly up to three or four hours longer."

"The main issue is when you are independently doing treatment at home when I have severe reactions the responsibility is on you to deal with it and address the problem while coping with a severe medical reaction which is stressful."

"Less time."

"Didn't feel as good."

"Because it's weekly, feel like it's running my life. I don't feel like I get a break in between the treatments. As soon as I am finally not in pain, and all the swelling is gone, it's time to start it all over again."

"The numbing cream that I got prescribed is of huge help during the infusion, as there was a point before the switch when I was finding it incredibly hard to insert a needle as it was so painful."

"Positive impact."

"The switch is more painful to my husband."

"Takes longer to set up rather than being able to go straight into it. There’s more build up emotionally."

"I was worried about the side effects of a different brand and frustrated that the change was done to, rather than with me."

"Worried nervous scary."

"Just worried about any side effects."

"Switched product so was worried as had some side effects. Also switched to using a home care provider to supply product."

"As with other IG changes there is always the concern about any reaction or if the new product will be suitable and ‘agree’ with me. Until you have taken a few weeks worth of it you can’t be sure."

"I have had two switches since my original product wasn’t available. There has been no monitoring of this second product, just left to me to contact them if I have problems. I develop numerous nodules under the skin at each site, they seem to be permanent and due to the amount, it is almost impossible to tell if this 2nd product is also causing them."

"At the time it was a big effect and a lot of worry, but it was a while ago so now life had moved on."

"I think it was I had to change something that wasn't broken to me though I understand the fact it was going to be taken off the list."

"I started the switch in January. I received a few treatments. My health declined fast. I was sick constantly and missed a ton of work."

"I dread the process. It's annoying. I don't have much hand strength and the fight with the bottles is draining."

"I came off it for ten years as I was having a reaction but had to go back on it as getting lots chest infection but they do it in stomach now."

"The extent of how hard I had to push to be heard by my consultant caused significant depression and anxiety."

"Less fear less pain reaction does go down quicker much nicer to do."

"I felt quite anxious and stressed about changing product."

"Fear of having a reaction to a new product after being on the same brand for so many years."

"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."

"Having side effects after treatment again wasn’t particularly nice. It seemed to really upset my body for a few months."

"Frustrated and sad for my son."

"I was a little anxious that the new product would have side effects, but so far it is OK."

"Doing subq already a mental load - was also diagnosed with inflammatory arthritis and switch delayed being able to begin treatment for that leaving me in pain and losing money from time off work causing ripple stress concerns about personal finances."

"More infections as not as effective."

"It was a concern at my first switch session whether I would react to the new treatment. It was given in hospital to mitigate this risk and I felt reassured by the staff. However, it was still a worry until I had completed the infusion."

"Adverse reaction made me very unwell. After 6 weeks am still not fully recovered and have missed an infusion as a result increasing my anxiety concerning infection."

"Concerned of any new side effects."

"It’s stressful swapping."

"Just initial anxiety."

"A little worried when supplies seem to be short."

"I was apprehensive when I heard about the framework changes early this year. I was given time to prepare for the switch and so it was fine. It is my first switch, so I did have some concerns."

"See previous answer - the inability to travel extensively is very upsetting. I was always told that my illness shouldn't limit my life - this is no longer true."

"Condition much better managed, less infections better qol"

"I hate my treatment full stop. I hate going into hospital and bring a patient and reminded how I am othered. I hate having to accept something I don't want."

"I was anxious how the change would affect me."

"Anxiety of switching to a new product when the last one had been so successful. A huge worry about reactions."

"Side effects of new brand takes longer to go away."

"I was worried the new brand may not suit me, and worried about the extra liquid that would need absorbing."

"It was life changing and wonderful. I never worry about doing my infusion now."

"Anxiety."

"I was a little sad to switch away from [named IG product] because I participated in the clinical trial some years ago - for which purpose I chose to invest a considerable amount of time (and travel money to and from the hospital during the clinical trial)."

"Getting used to yet another therapy."

"I was very worried I would run out. I was also worried about having to ask for time off work. Going to a different hospital, where to park etc. I am quite a confident person, but when it comes to my health, attending appointments etc it triggers some anxiety. Things like not being told the car park was cash only. I have every parking app going but rarely cash so that was very stressful. I nearly gave up and drove home."

"Upset because I have felt so ill after treatment."

"I find it frustrating with all the individual components to do a weekly push compared with just getting a single syringe and needle out and taking 5 minutes to do a daily push."

"Just a bit of upheaval when I was already struggling with breathing/lung condition and hospital admissions (at a different hospital). Also adapting to using home oxygen. It could have been timed differently. But it was already in action."

"I was concerned that I may not tolerate the new medication as well."

"I don't look forward to how I feel after."

"Swap in the hospital didn't go well, caused high blood pressure therefore anxious about the next infusion done at home."

"I have had very bad side effects from switching medications in the past which have taken a year + to resolve and thus was very worried about changing again. Fortunately, it has been better received by my body."

"Severe anxiety and worry. On one occasion I was told I was switching and the new brand was prescribed but then it never came and they couldn't get my regular brand prescribed so my transfusion was cancelled. The first month after finally switching I felt very tired, bad eyesight, muscle twitches, leg weakness. Usually after my infusion I feel better with a mood and energy boost but that never came. It’s been very unsettling."

"Due to long term use of a blood donor derived product, I have concerns about safety. I researched about the new infusion product, as different preparations have long term impacts such as the choice of stabilisation agent which can affect kidney function, the possible presence of anti IGA antibodies, the methodology used to screen for Blood Born Viruses and to treat the product."

"When I had the new product delivered, I was told it was going to have to be stored in the fridge. I found the change of product challenging as the [named IG product] gave me no side effects and didn't disrupt my week, so when I then had to change to [named IG product], which made me feel dreadful every week, it made me struggle emotionally."

"Uncertainty."

"With the problems with the first switch and being unable to identify any new ones accurately with this second product I have had no opportunity to have a discussion about this at all. I have not had any discussions regarding further options and find the indifference by Consultants to problems with the new products difficult to understand."

"I am more anxious because it takes longer and I do not trust NHS to give me the best product as I think they use the cheapest product."

"Making very unwell for 48 + hours I am missing treatments because of this leading to extra fatigue & anxiety about infection."

"Stressful."

"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."

"The change happened when I was already quite anxious about Covid so the 2 combined did increase my anxiety around my own health."

"A tiny bit anxious as my brand was working brilliantly but it was a like for like change so fine really."

"Concern about dealing with power cuts but was resolved quickly."

"Sometimes when feeling unwell this can get you down mentally."

"The new product [named IG product] has been much more painful to administer, producing swelling at the site and with lingering and severe bruising and hard lumps around the site. The infusion is now very traumatic for our boy (22 months old) and for us as parents, increasing our anxiety and causing severe distress for us all around the time of infusion. This never happened with the former product [named IG product]."

"Affected me in that I was using some equipment that hadn't been used before even by the immunology nurse hadn't seen/used before during switch appointment which was a little stressful."

"I had anaphylaxis with the changed recommended ivig."

"I was concerned because I was on [named IG product] for 8 years and fine and a different medication could have cause different side effects but the [named IG product] is fine."

"Having the security of the hospital administering it to doing it yourself can be daunting until you get used to it."

"In a positive way - move to a IVIG that is more tolerable."

"A bit stressful thinking about possible side effects."

"Annoying/ inconvenient."

"Caused me some anxiety and stress, they wanted to switch me right before my wedding and I was scared of new side effects."

"I'm struggling with my health and I can't understand how reducing the choice of NHS products will help when there are shortages. In addition, the switch has caused more appointments and phone calls with the delivery company and hassle that I don't need."

"Anxiety having to travel 53 miles to the main hospital for training. Anxiety about possible side effects."

"Not having medication in a easy single location makes it difficult to remember to administer it. Also, the new brand is a bit more irritating when administered."

"I was anxious about the switch but it has worked out ok."

"I feel uneasy changing to a different brand after having confidence in a product I've used without a problem for nearly ten years. I understand the immunoglobulin comes from a different donor pool and the new manufacturer can't demonstrate the same length of safe administration."

"Just the change and how I might react."

"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."

"I felt unheard, uninvolved, dictated to, and given a product with a slightly higher risk of side effects (non-proline)."

"Much prefer treatment myself over going to chemotherapy unit for infusions."

Analysis

The comments are predominantly negative to mixed. They highlight a high emotional burden linked to uncertainty, loss of control, and prior negative experiences. There were some positive or neutral experiences, typically where communication and outcomes were good.

Key themes were:

1. **Anxiety, fear, and anticipatory stress** caused by fear of the unknown side effects or reactions, anxiety about the effectiveness of the new product. There was fear from past adverse events amplifying anxiety, and this leads to hypervigilance when switching is imposed.
2. **Loss of stability and disruption of 'what works.'** Patients highly value product stability and experience loss of control, autonomy, and agency during switching.
3. **Physical side effects lead to a psychological impact** and strongly influence well-being.
4. **Lack of support, communication, and monitoring.** Poor healthcare engagement was a major stressor - insufficient information and feeling unsupported post-switch. When communication was good, anxiety decreased. Communication quality is a key moderator of emotional impact.
5. **Treatment burden and lifestyle impact.** Switches often increase the practical and emotional burden due to more complex administration methods and increased frequency or duration of Ig therapy.
6. **Transition and change fatigue.** Patients described repeated switching cycles and an accumulated psychological burden.
7. **Logistical and system-level stressors also contributed to general stress and anxiety.** The stressors included supply shortages, travel requirements, and equipment changes.

A smaller group reported positive adaptation with improved tolerability for the new product and reduced anxiety after a successful switch. These were associated with good preparation for the switch, an effective product match and supportive clinical care.

Theme: the impact on the ability to manage Ig treatment independently

"No preloaded syringes now. It has to be transferred from the vial to a syringe."

"Hurts more and takes longer"

"No need for a nurse. I could infuse myself."

"Not needing the fridge, not a concern when travelling, freed up space the fridge had occupied"

"The absence of prefilled syringes has had a severe impact on my child's life. She travels a lot, both for work and leisure (and recently for education) so the option is to only travel for maximum of 4 weeks so she can continue to have IVs at home or return to subcutaneous which is a logistical struggle when travelling."

"Switched from IVIG to SCIG & I love that I can administer myself at home instead of day long appointments at the hospital and weeks of side effects."

"Due to the reaction I took I made the decision to stop taking my immunoglobulin and now I've been without treatment for maybe two years coming due to the staff shortages in Scotland I haven't been able to be reassessed by an immunologist"

"I now infuse once a month not every week."

"I find weekly infusions rather difficult to manage. The needle sites don't have enough time to heal. I used to have bi-weekly infusions, so from time perspective it was better, but the side effects were worse."

"I still have side effects from the new treatment, but they are not as bad. It's just the frequency and the time required to administer (which now nearly doubled, given that I am doing it twice rather than once every two weeks). I do hope the speed at which I can do an infusion improves in the future, as I am still getting used to the new process."

"Fewer sites - as a result I keep up better."

"New product is same dose but more concentrated ie. 40ml instead of 50ml but am still using 50 ml syringe so a lot more difficult to attach to pump as plunger isn't fully retracted - gave up on one treatment as couldn't manage."

"It was a prefilled syringe but is now a vial."

"I have regained some of my life as side effects are now more manageable."

"LISTEN TO PATIENTS!!! We really do know our bodies best."

"I was getting massive red marks the size of a dinner plate - very hot and sore and now get hardly any affect."

"The type and consistency of the new one is different and more challenging to use and is thicker, taking more time to infuse and more uncomfortable for my young son who receives it."

"The switch from IV to Subcutaneous means it is easier to self-administer which is important for me."

"I do sometimes dread doing it as it’s every other day. However, I am terrified of the pain of Aseptic meningitis so ensure I just get on with it. I do get fed up though as barely a day goes by when I don’t have to consider my PID."

"My husband does the needles as I can't do it to myself, I also struggle with anxiety around infusions and sometimes miss them due to I don’t want to do it."

"I've had to take time off work to receive treatment."

"Awaiting decision on what product I can have due to adverse reaction to the new product."

"It has to be refrigerated."

"The set up is easier and there is less waste. The time taken is longer, but this is not an issue as I am retired."

"In general, it has not affected me because I can do IVIG with the new brand. However, I like to travel frequently and I cannot do IVIG when travelling, so I used to take pre-filled syringes of [named IG product] when travelling. Separate syringes and vials are impractical and cumbersome for long trips. Now that [named IG product] (and therefore pre-filled syringes for subcutaneous injection) has been discontinued, I will no longer be able to take long or complicated trips, which will have a major impact on my life."

"Now infuse sub-cut weekly in my own time with very minimal side effects instead of a full day off work to have IV at hospital every 3 weeks and the experience significant side effects."

"I did intravenous for 30 years at home and now do subcutaneous which is so very much easier."

"No major effect other than the process is more timely and difficult as it involves drawing the solution from a vial into a syringe."

"Self-administered subcut at home works much better than having to travel to the hospital for IV."

"The requirement to keep the product cold (and in the fridge) has made things a little more difficult, but it's fortunately not too big an issue."

"If people knew how easy Daily push is, I am sure they would all want to do it."

"My body cannot tolerate it as before so i cannot work after and must rest - so it has changed my day every third week - but I guess my body will adapt."

"Changed from pre-filled to bottles. Lots of waste due to bubbles."

"More liquid to infuse which takes longer."

"Having to fill the syringes myself. I never feel sure I’ve done it correctly."

"The dose has remained the same but now more concentrated into 40mls rather than the 50 mls before but I still use a 50ml syringe and pump and it is sometimes really difficult to connect the pump to the syringe as there is a portion of the plunger which does not retract fully. It can take numerous stressful attempts to align it correctly and on one occasion I simply gave up."

"I have adverse side effects to current product including fainting which means I cannot administer alone."

"Although the change was not my decision, and I initially found the change quite stressful and even fainted the first time I did it home, I do now prefer doing subcutaneous therapy at home rather than IV at home, which I was previously doing. It feels less dangerous."

"Very nervous in case I did something wrong. No direct number for help. You leave a voicemail and wait for a call back. Not suitable when halfway through an infusion and have a problem. Also only having annual clinic appointments which I feel is too long."

"Additional time resource to use new supplier moved from pre-filled syringe to vial. Extra 45 minutes to 1 hour per infusion session."

“Because I had one allergy situation when they switched the iv medicine.”

"I now only self-administer once a week."

"Switched from travelling to hospital to administering at home which is easier and less time consuming."

"There is more preparation involved but the actual infusion is more relaxed."

"Volume has increased so infusion takes longer."

"Additional time. As a person that works and commutes 2 hours per day Monday to Friday any additional time impact on family and working/home life such as this pays a toll."

"This new product needs to be refrigerated and therefore now takes up more space. I was also previously on pre-filled syringes which were easier whereas the new product is in bottles that need to be drawn down, feels like we’ve gone backwards."

Analysis

The shift in Ig products and formats has created a mixed but strongly polarised impact on independent management:

1. **Greater independence** and improved quality of life for those who moved from IVIG to SCIG or gained home-based administration.
2. **Reduced independence**, increased burden, and in some cases loss of treatment continuity for those who lost prefilled syringes, must draw up from vials, or face thicker/more painful formulations.

Anxiety, fear of doing it wrong, and emotional fatigue appear in over a quarter of responses.

The single most consistent message across negative responses was that prefilled syringes were a critical enabler of independence. Their removal has disproportionately harmed people who travel, work, or have limited dexterity or confidence.

Theme: unlisted survey factors that patients feel are important in guiding decisions to switch IG therapies

"Emotional wellbeing."

"1. I can travel 2. The IV was damaging my veins 3. Had to ask my Dr. to change."

"It's a little more convenient."

"Availability of like for like products (prefilled syringes). Cost and safety etc are of course highly important - you can't change to an unsafe, ineffective, more expensive product. But if the new product does not allow you to lead your life as you did previously, surely that needs to be noted."

"Due to where I live within Scotland, I have been told the waitlist to see an immunologist is 2-3 years."

"Due to my postcode determining my level of care."

"Some products definitely suit a person better ie side effects and ease of dose."

"It shouldn't matter if one brand is slightly more expensive than another- supply should be allocated based on patient tolerance."

"Allergies."

"The patients trust in the knowledge and judgment of their consultant and the relationship between them."

"Patient's wishes about switching when there is no actual clinical need to switch product."

"If NHS is guided by cost in a long run, it may not be cost effective as assumed if a patient has severe side effects or product is not working well. Admission to A&E, GP appointments, cancelled infusions due to side effects etc. if it works well for the patient and the patient is stable, why change it ?!"

"Assistance and info from manufacturer."

"Minimising side effects is extremely important."

"Most effective treatment."

"Cost to healthcare trust."

"I have a port a cath and do all my ivs through it as home therapy."

"I think there is a real issue with treating patients as real, living humans with complex feelings. We are sick - constantly. We need you to work with us and HEAR us - medical gaslighting has to end."

"It's all important but it's us that has to live with disability and I was almost laughed at by my previous nursery when I said… it's hurting and the reactions are sore. She said, that's just to be expected. Until she actually saw it and then realised I was not kidding. I was finally taken seriously after months and months of pains and swellings. So, patient knows best, patient has to live with, we are so so lucky to have the NHS support though, so I'm aware we as patients also have to do right by NHS too."

"Side effects ...I feel like I definitely get on better with some brands of IVIG better than others."

"Product quality and safety."

"The psychological effect on the patient."

"Support of mental health issues and counselling should be offered throughout the process."

"It's a supply and demand issue different areas different rulings and decisions."

"I think it is a cost element."

"Reducing waste and ability for recycling of packaging and non-clinical waste."

"Current government doesn't care about immunocompromised patients, we've been given old COVID vaccinations too."

"No option given, as previous brand removed from NHS."

"Opportunity to discuss and reassurance."

"It’s so expensive anyway, not sure the cost would impact but better control on ancillary items would help, I get all sorts sent out."

"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."

"Side effects."

"I understand that there are only 3 products available now for subcutaneous use which gives very limited options."

"Mental health."

"It made a difference the nurse being with me, first time using new immunoglobulin to make sure there was no reaction to new solution."

"It's all about getting patients off ivig."

"Not everyone can tolerate the same products and it’s frightening when a new product doesn’t suit you, bad side effects or reduces your normal daily capabilities i.e. less energy as some can leave you with dreadful fatigue."

"Administration at home always preferable for us."

"If infections reduced or controlled on current tx then don’t change it!"

"Cost should not have any effect, it’s our lives..."

"Safety and effectiveness. Perhaps having immunoglobulins coming from the same regional population as the recipient, or at least one subject to a similar potential infection profile."

"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. In addition, some patients may have been changed to products that will not be as suitable or as effective as their previous product."

"I do not believe as a patient community we should accept this type of cost cutting exercise on a regular basis."

"Happy to switch products for any reason if benefits NHS in any way!"

"Mental wellbeing and stress of the change."

"Fear of scig not working well enough or that I have intolerance."

"Cost and security of supply is an issue, but I would have expressed a preference for the UK derived L-Proline based product... had I been asked"

"It’s clear the NHS is being motivated by cost savings at the expense of patient quality of life."

"These questions are very simplistic you have to consider all aspects together."

"Communication with patients before any change."

Analysis

1) Patient-centred care & autonomy was a strong, recurring theme. There was a desire to be heard, respected, and involved in decisions. Frustration was expressed with top-down switching decisions. Patients see switching decisions as not just clinical but deeply personal. Lack of engagement risks mistrust and perceived “medical gaslighting.”

2. Side effects, tolerability & individual response to a product were the most frequently mentioned practical factors. The comments highlight the variability between products, the importance of minimising adverse effects, a fear of intolerance and reduced functioning and the need for product choice and flexibility. Overall, the comments reject the idea of “interchangeable” products, with switching being seen as risky if individual tolerability differences are ignored.

3. **Quality of life & daily functioning**. Treatment must support normal life (work, travel, energy levels). Convenience and home administration are important. There is a fear of fatigue and reduced capability after switching. Overall, patients evaluate therapies not just clinically, but also the impact on their lives—a major gap in traditional procurement-driven decisions.

4. **Mental health & emotional well-being impacts.** This theme was explicitly and repeatedly highlighted. Switching creates stress, fear, and anxiety. Switching decisions are psychologically significant events, not just logistical ones. The emotional impact is often overlooked in policy.

5. Trust in clinicians & relationships. Trust in healthcare professionals influences acceptance of switching with a value placed on continuity and reassurance. Negative experiences reduce confidence.

6. The cost vs value debate was a highly polarised theme. There were two opposing perspectives: pragmatic/accepting – happy to switch if it benefits the NHS and anti-cost prioritisation, with concern about false economy (A&E visits, dealing with complications). Overall, patients recognise NHS constraints, but fear cost-driven decisions override clinical and personal needs.

Additional free-text comments received

"I was informed by my hospital pharmacist of the change and was told the new product was sourced from the UK. During the phone call I was told the clinic would run the infusion at a lower rate and monitor. Which they did. After 3 infusions the clinic started offering me pre-meds, it appeared they should have offered when the switch took place. By the time I was offered I had had no reactions and believed it would be of no benefit to start taking pre-meds at this stage. All in all, the switch went smoothly for myself with no reactions. The only difference is, the infusion can be administered quickly, and safely."

"If the process is monitored, and the reason for switching is in the patient best interest it’s better than the alternative of no immunoglobulin."

"It was no big deal."

"I was initially a bit anxious about switching products because [named IG product] worked so well. [named IG product] is fine but I find I’m a bit more tired on it but not to the point I would switch products again."

"I am pleased that [named IG product] has worked out for me and that the NHS is probably saving money which could amount to millions over the next few years."

"Have to say that my hospital is very supportive and generally will get back to me same day if I have problems or questions but seems they don't really have a say in what product we get apart from choosing subcutaneous, ivig or daily push."

"Overall, it has not been no problem at all (thus far), and although it wasn't explained in great detail, I was aware of its happening and some of the reasons. But I have complete faith in my consultant, and I wouldn't have the level of health, and the quality of life I have at present, without them and their team."

"Since switching products I have noticed some lumps appearing on my abdomen post infusion, some of which have remained. This concerns me. I have self-administered SCIG for a number of years, and changed product previously, but have never experienced this issue. It may not be related, but I would be interested to know if other patients have experienced this phenomenon."

"I switched as cannulas become difficult to insert, I have really small wobbly veins. Subcut will be better for me in the long run."

"I am currently experiencing severe side effects with the product I have been on since mid-2022. It is highly frustrating to get health professionals to take my concerns seriously. Despite clearly evidence that something is not right and is consistent with product description of side effects in the leaflet."

"It was no problem to switch."

"This switch was smoother than the first one, but it could still be better. I don't like needles much, so perhaps that's why I am having difficulty adjusting to SCIG. Initially I was on IVIG, but as I have central line for other reasons, I never needed to use needles, until my first switch to facilitated SCIG and now to SCIG. I would like not to have swellings. I would like it not to hurt."

"I do feel that cost to the NHS was a big factor in the switching of the product."

"Honest communication about the need for change, and reassurance about the potential impact of change, would have been beneficial."

"I have had 4 changes in specialist consultant and each one has wanted to stop my IG treatment."

"Would much prefer to go back to my old product which took 2 hours to infuse as opposed to the 3 hours it now takes. I do it more slowly in order to allow it to absorb better and hopefully not develop more of these nodes- thought to be scar tissue, but no one is sure and don’t really seem very interested which I find strange considering this is a new product."

"They switched me back to my original brand after months of sickness and labs dropping."

"My hospital [named hospital] have an excellent department so that made it as easy as possible although not ideal for me as I was happy with [named IG product]."

"I am happy to have been able to switch therapies but not at all happy that me ending up acutely unwell in hospital is what finally prompted the switch. I have been treated abysmally by those ‘in charge’ of my care. Thank GOD for the nurses - they are so wonderful."

"Thank you for asking my opinion. it doesn't really happen with a PID."

"Had a few side effects but has improved on 3rd dose now."

"Not great as had a reaction"

"I know this is anonymous, but the staff at my hospital, [named hospital] were excellent in how they administered the switch. From the moment it was first mentioned as a possibility to the sign off on the new product and home delivery, I was kept fully informed with as much choice as was possible within the limitations of the situation. They are a credit to the hospital and to the “world” of immunology treatments. Thank you."

"I thought the whole changeover - including one appointment where I received a test dose to ensure I had no adverse reactions to the new brand - was handled well."

"NHS England need to stop doing this, this is the third time since [named IG product] was scrapped."

"I was switched from [named IG product] to [named IG product] same dose but slightly harder to take. I feel washed out after taking my infusion."

"The letters, e-mails, phone calls and the appointment with the Specialist Nurse were very comprehensive. Although I had no choice in the switch, the reasons for this were clearly explained and the support required was very good."

"The two most recent changes have been beneficial due to increased maximum infusion rates of the products and therefore less time on the ward."

"In my personal experience, I have full confidence and trust in [named hospital] staff, who have always been very good at explaining why a change might be required and the consequences."

"My team are very supportive but utterly understaffed, I could not make my annual appointment due to unforeseen serious incident, next one is over a year away! You sometimes feel very alone with this."

"Luckily I've not encountered any problems switching product. It has been well monitored and my specialist nurse is keen to make my infusions easier and quicker."

"On this occasion, I've had a very positive experience in switching Ig products. In the past, however, I've experienced allergic reactions (mainly with IVIg products). I'm very pleased that there has been no repetition of that this time!"

"My nursing team were lovely but couldn't do anything about the central decision."

"The switch was handled efficiently and I felt my Nurses cared about me."

"It’s worrying to have to switch when you are happy with the product you are already using, but luckily the new product has been ok so far."

"I was given total control over decision and it was a no brainer. Life is so much easier now."

"At the beginning, the phasing out of the [named IG product] to the [named IG product], meant that the old product's shelf life was reduced and I was getting mixed batches of product, and storage changes as the [named IG product] did not need a fridge."

"I was slightly concerned as any new treatments can have side effects, but the nursing staff took time to explain and reassure me. The first new infusion was done much slower until I was sure there were no ill effects, and it's been plain sailing from then on."

"My immunoglobulin levels were completely undetectable when I was diagnosed so immunotherapy makes a huge difference to my health and quality of life - for which I will always be grateful."

"I have switched many times over the last 50 years. Mostly due to change of administration and advance in medical techniques. And mostly for my benefit. I moved from painful intramuscular injections from age 10 to 20 to intravenous that was spread out and had better coverage. To later subcutaneous in the early 2 thousand. That meant better independence and let hospital trips. So, in those cases, it was welcomed. Cost and NHS policy have been more recent issues."

"Partly because the products are used more widely for many health conditions and have become more expensive due to demand. Or so I am told."

"Also, plasma has only just been authorised in the UK for use in blood products due to historical mad cow disease. So maybe things will get cheaper 🤔 ."

"Sorry for the long post. But thanks for opportunity to express myself."

"The new medication is slightly more difficult to administer."

"It was money driven and not well explained or well prepared for - and not universal in EAST England."

"The ‘project management’ of the changeover was very poor. The pre-meds I was given to reduce my bodies reaction for the first 2 infusions came with incorrect instructions which made me more unwell. Despite giving the distributors, a months’ notice as to the date on which I would require the delivery by, I only received it the day it was due after having to manage the various moving parts myself (ie chasing pharmacy to sign off the prescription). They also did not deliver the correct syringes, and it took a few weeks of constant chasing to resolve this."

"Switching brands is traumatic as its very worrying and triggers your fears and anxiety. You don’t want change especially when everything was already going very well and for the first time in ages you aren’t as sick. It’s also important to discuss this change and rates its administered as your body could possibly not tolerate the change very well. A lot of people need pre-medication for this exact reason."

"It takes a while to build up trust with your medication and your care giver that is prescribing you it."

"I have already changed products four times over the past 5 years, hopefully no new changes!"

"I have not had a good experience so far and still have doubts about the product I am using now. I would have preferred to remain on the one I had used for years but not discussed or given that option."

"The hospital wouldn't give me one brand because they said it had to be kept in a fridge, but when I looked it up, it didn't need a fridge but the hospital were adamant so another brand was given. This was annoying!"

"Finding another alternative has been difficult, slow & indecisive from hospital."

"So far so good but probably the older i get if i had to change again, you're always worried you may have a reaction."

"[Named hospital] are trying to reduce usage of IVIG to minimum mostly for cost."

"I have had two IV treatments with the new product but not yet started administrating it at home so some of my answers are informed by this; particularly in relation to satisfaction with the new product. Currently neutral but still scope for it to be better once I'm more used to it."

"Whilst the team I’m under is amazing I do feel higher up people don’t care about anything but costs and forget people are individuals with needs and fears. I got the impression this drug is similar to your old one get on with it, you can’t possibly get different side effects."

"Am very happy with new supplier and product."

"We would be happy to be contacted further about our experiences and to discuss with others or contribute our data to build up a bigger picture of [named IG product] as a product."

"I was very happy with response to the problem I had with the previous product and the care I received."

"Grateful to CNS in trying multiple options to minimise side effects."

"My immunology consultant is based at [named hospital] and I am generally very well supported."

"Although there wasn't a discussion about it, I think it has worked out better for me having this new product rather than my previous product. It seems to suit me better."

"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."

"I believe we are blessed to live in a country where you receive NHS medicines etc and that's why I prefer to leave any therapeutic decisions to the professionals. They have never let me down."

"I have been having Ig therapy for over 20yrs now and have noticed over the last two switches of product that they are less effective than the original serum product. I'm also made more aware of the cost of the product which is often uncomfortable to think about."

"I think the [named hospital] handled it very well in my case."

"Although it has taken time to adjust the training has been very good. As I said side effects are more noticeable, but I still prefer being at home. I feel lucky to have been approved for this treatment."

Analysis

The responses again show a mixed experience overall, with negative comments accounting for approximately 25–30% of responses. The biggest drivers of satisfaction are not just the product itself, but how the change is handled and how patients are treated throughout the process.

Main themes were:

1. **Clinical outcomes & side effects.** Many patients cited a smooth transition to new products with mild side effects improving over time. However, some patients reported significant adverse reactions, underlining that not "one-size-fits-all" in terms of product tolerability. Unresolved concerns were reported, including persistent lumps after switching to a different product.
2. **Trust in healthcare teams vs system decisions**. Strong trust and praise were expressed for healthcare teams, but frustration with "central decisions", perceived cost-driven policies and lack of clinician autonomy.
3. **Support & care experience** showed a strong theme of variability, highlighting the staffing pressures some immunology centres are under to deliver care.
4. **Autonomy & involvement in decision-making.** Responses show a mixed experience, but there was an expectation that patients want involvement, even if the choice of products is limited. Recognition is needed of personal history and concerns.
5. **Adjustment burden & anxiety with switching** creates psychological stress, even when clinically acceptable. This included anxiety before switching (fear of reactions, disruption of a trusted routine). Repeated switching increases fatigue, with some patients reporting frequent changes.
6. **Experience in the administration of a product.** The practical impact on daily life, such as the ease of administration, the time taken for IG infusions and the pain experienced, was a major determinant of satisfaction.
7. **Process & logistics issues.** Some respondents reported problems, including delivery delays, incorrect supplies (e.g., syringes) and prescription delays. This was a minority but a high-impact issue.

Healthcare professional free-text responses

Theme: NHS communication and information about IG therapy switches.

“Very poor not just poor. no discussion simply told to do so.”

“The message was sent through to pharmacies. Initially it was not clear to me what the impact would be on patients. The timelines have changed and I have gone from having almost complete control over the immunoglobulin to give to my patients, I am now beholden to the pharmacists and commissioners to dictate who gets what.”

“Guidance issued by NHSE re: applications for pts to return or remain on reserve product. States ensure all options exhausted including 'homecare nursing'. Trust are only reimbursed for the dispense and deliver element of homecare, not nursing. In this situation it is not clear who would fund the homecare nursing element, if considering an application for a patient to return to a reserve product. All trusts in the UK are being tasked with saving money, hence are unlikely to agree to fund an expensive nursing service, when it would be free for a patient to switched to an alternative product and waste months’ worth of product in the patients home that the cannot use due to side effects. Etc.”

“We were not given a clear timeline of when to switch patients over to the new contracted brands which caused a lot of confusion.”

“Recent advice was to change at a specific time however this did not take into account supply currently held which needed used first to ensure no wastage.”

“Communication is often limited and supplied later than would otherwise be helpful.”

“It was reasonably clear what was expected, however patient info etc was very late being released. Guidance around applications to remain on or return to reserve product not clear and no guidance as to who should answer statement written.”

“If I had not attended the BSI-CIPN in December I would not have been aware of the switch over until March as that was the first bit of official communication sent to our department.”

“Unsure of which products to use for which condition.”

“I was told but the amount of work for staff like me was enormous and it was not fair that it all fell to so few people to arrange the switch and train patients/carers (for SID patients). I had to type my own letter as the one that was given to us by panel was far too wordy, most patients would not have understood it and there would have been panic had another letter not gone out with it in plain terminology.”

“The information does not filter down so well. It's hard to know what the consultation process has been with clinicians working in practice, but their communications have been limited, defensive or reactive. It didn't look like impact on clinical time was considered during the decision to make such a big change so quickly. A more phased adjustment in the contract and allocation could have had a lesser impact.”

“I didn't hear first from the NHS.”

“The new framework did not consider important clinical needs for patients.”

“Delayed communications with sometimes unrealistic demands.”

“We managed to send the letter to all the patients regarding the switching the product, apart from Satellite unit patients.”

“Our consultant is working at national level. However, our concern about limiting 16% products was not resolved.”

“In Wales, we have a very clear 'traffic light system' that allows for choice, clinical appropriateness and agile stock management. We have excellent communication. As we are not aligned to NHSE, we received no communication about NHSE decisions regarding removal of products. I asked colleagues in England, but they told me that they had not received any information either. The decision was presented at BSI CIPN, but no questions were allowed.”

“While non-clinical switching is not undertaken in parts of the UK such as Wales, it is clear that communication in England has been very, very poor with a lack of answers to questions and real concerns. Edicts are passed down during official talks, the audience infantilised, concerns are brushed aside as teething troubles amidst the self-congratulation and unsurprisingly there is no time for questions.”

“No official information was made available to our service, however that is possibly because we have a separate Welsh framework and contract.”

“Non-clinical switching has not occurred in Wales. From what colleagues in England have said, the communication has been very, very poor with a lack of answers to questions and real concerns. Significant concerns are not being heard, whilst policy/finance makers seem to be praising it as a cost saving when in fact teams have significant concerns and the longevity is shaky. Another NHS budget cut that negatively impacts patient care and future planning/crisis management seems to be forgotten.”

Analysis

The overall sentiment is strongly negative. Only Wales-based comments mention positive experiences, but these relate to Welsh systems, not those in NHS England. Feelings of anger, frustration and confusion were highlighted alongside disempowerment with loss of clinical autonomy. Concerns were raised about patient safety related to inappropriate switching.

The major themes identified were:

1. **Poor or delayed communication** - staff felt uninformed, unprepared, and excluded from decision-making. Many professionals learned about changes only through conferences or colleagues and not through official channels.
2. **Lack of clarity in guidance** - either too late, too vague, or not clinically grounded. This created uncertainty in clinical decision-making and operational planning.
3. **Operational impact burden** - switching required training, patient communication, stock management, and administrative work — all of which had to be adequately planned for.
4. **Supply chain and stock management issues** with misalignment between guidance and real-world stock, leading to waste or inefficiency. This created tension between clinical autonomy and procurement constraints.
5. **Perceived top-down, non-consultative approach** – sentiment of clinicians feeling disrespected, ignored, and excluded from decisions that directly affect patient care.

Responses indicate the need for the following:

- ✓ Earlier communication with realistic timelines
- ✓ Clear, clinically informed guidance on product selection and switching

- ✓ Transparent rationale for decisions
- ✓ Consultation with frontline clinicians before implementation
- ✓ Funding clarity, especially for homecare nursing
- ✓ Patient-friendly communication materials
- ✓ Respect for clinical autonomy

Theme: the availability of adequate clinical guidance or support for managing IG switches

“Guidance often reflects individual opinions rather than consistent national protocols.”

“No guidance was provided on how to perform switchovers.”

“Communication has been poor.”

“Services are already stretched without multiple switches.”

“Our team is responsible for training others, which increases workload.”

“Centres are managing switches differently across the country.”

“Some pharmaceutical companies have produced helpful information materials.”

“Centres have their own protocols which do not always align.”

“Lack of forward planning for staff implementing switches.”

“Variation in practice around infusion numbers and monitoring.”

“Smaller units have limited staff to manage the process.”

“The BSI statement was helpful in providing clarity.”

“Some support from NHS England but insufficient from other sources.”

“Letters from NHS England were issued too late to prepare properly.”

“Company representatives sometimes supported explanations to teams.”

“Guidance for clinical switching is strong, but not for non-clinical switching.”

“In Wales switching rarely occurs so guidance has not been needed.”

“We have not yet had to undertake non-clinical switching locally (Wales).”

“Wales has a robust system in place for managing switches.”

“The question is difficult as non-clinical switching does not occur locally (Wales).”

Analysis

The variation and inconsistency in guidance lead to fragmented practice and uncertainty. Local autonomy fills the gap, but this creates inequity and inefficiency. Teams felt reactive rather than prepared.

Implementation burdens fall heavily on clinical teams. Guidance alone is insufficient without workforce capacity, with smaller units disproportionately affected.

Wales has a much lower switching frequency and has a more stable system, reducing the need for extensive guidance. This contrasts with England's more dynamic switching environment.

Theme: the impact differences between organisational/service level and patient-requested switches

"Organisational switches are typically done across a large group of patients within a service, which increases workload and complexity."

"Alterations to tenders have caused a huge impact on services and workload."

"All products have broadly similar safety profiles, but switching still requires time and monitoring."

"With organisational switches, usually multiple patients are affected simultaneously, which increases pressure on services."

"We have not had any organisational-level switches locally."

"The volume of patients needing switching when a contract change creates a major operational burden."

"Large numbers of patients switching simultaneously create workload pressures."

"Enforced switches can create a lot of extra work and concern among staff and patients."

"Lack of early engagement, information sharing and planning makes switches harder to implement."

"Increased staffing requirements and administrative workload when multiple switches occur."

"There is a significant burden on nurses when products change."

"Switching creates additional workload while maintaining patient safety."

"Very time-consuming to communicate changes and monitor patients after switches
Organisational changes cause more stress for patients."

"I have had very heated discussions with colleagues regarding switching decisions."

"We recently changed contract brands which required significant coordination."

"Timing of switches depends on current patient supply and logistics."

"Haven't seen any patient-requested switches."

Analysis

The responses indicate a significant operational burden caused by organisational-level product switches, driven by contract/tender changes, poor planning, and the simultaneous impact on large patient groups. Staff describe increased workload, coordination challenges, stress, and patient safety concerns. A recurring concern is the scale of switches, as organisational switches affect many patients at once, increasing complexity. This creates pressure on services, especially when monitoring is required. Staff must spend time explaining changes to patients, and internal disagreements can arise.

Theme: HCP perspective on what leads to a good patient experience for switching IG products

“Autonomy and patient choice are key to effective switching.”

“When patients are forced to change products, it can lead to anxiety and dissatisfaction.”

“Patients often feel they have no control when changes are organisationally driven.”

“Switches should be made jointly with the patient wherever possible.”

“There are many reasons a product may be changed, including supply and patient tolerance.”

“Switching for non-clinical reasons can undermine patient trust.”

“Occasional reactions with new products can occur after switching.”

“Some patients have experienced issues following switches.”

“Some patients tolerate switches well while others struggle.”

“It must be frightening for patients to suddenly change treatments.”

“Switching should always be in the best interest of the patient.”

Analysis

HCP perspectives highlight that patients value autonomy, shared decision-making, trust, and emotional reassurance. Negative experiences arise when switches feel imposed, unexplained, or clinically unnecessary. Patients want to be active participants in decisions about their treatment. Feeling *done to* rather than *worked with* can undermine their experience.

Theme: factors that should be considered for policies concerning switching IG products

“Artificially limited set of products and manufacturers. Plurality of supply reduces risk for situations when a problem arises with a particular product or its supply, enables a deeper knowledge of therapies for doctors and nurses in training, allows patients access to research and new developments in medications or delivery and gives them choice to individualise and optimise their therapy - this is simply good medicine. Situations where patients and nurses do not know which product will be supplied, where switches occur during a single infusion as not enough of one product is available in pharmacy, where no robust system is used to gather adverse events, prems/proms and especially where choice has been removed from clinicians and patients represents a profoundly negative outcome. This is all the more concerning when the stated purpose is resilience of supply and cost saving with the evidence showing neither is this approach more resilient nor will it be cost saving. The use of UK plasma is very much a positive however again the cost saving suggested at half the price is manifestly flawed as the collection costs are not factored in and are often fourfold those of commercial plasma collection centres.”

“There is a massive burden to nurses when product switching is not managed in a timely patient centred manner. It also has a massive psychological impact on patient and families with training, hospital appts and homecare have to be changed against clinical advice.”

“On the rare occasion we have to do this in Wales, we have seen it reduce compliance to treatment. In addition to this, patients are frustrated at the team for not being able to provide the same treatment. I imagine that in England where they are having to switch people just for perceived cost savings, this would definitely decrease patient trust. Your role has switched from clinician who helps patients make the best choices for them, their family and lifestyle to medical staff having to make choices on behalf of patients all based around costs.”

“Very time consuming to communicate changes, more significant with our very large home therapy cohort.”

“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.”

“Challenging to bring homecare patients back into clinics when switching products.”

“All switches are made based on clinical judgement in our service (Wales).”

“In Wales this occurs rarely due to existing systems.”

“The organisation and time that switches take up in services.”

“Price should not override patient wellbeing.”

“Trust and psychological impact on patients and families.”

“Differences in administration methods such as pre-filled syringes vs other systems.”

“Security of supply to reduce the need for future switches.”
“Consultation needs to be improved for future changes.”

“More stakeholder engagement is needed across the system.”

“Please retain clinical judgement in decisions.”

“Decisions about Ig switches should remain clinician-led.”

“More consideration should be given to staff and patients during switching.”

“The workload involved was not appreciated by government.”

“Our Trust has already made significant resource cuts.”

“Reduced access to facilities is affecting service delivery.”

“We used the opportunity to review services which had some benefits.”

“Data should be collected before and after switches to assess impact.”

“Very frustrated on behalf of patients.”

“Switching therapies should be based on clinical need.”

“The current NHSE mandate has created operational challenges.”

“We manage switches carefully and communicate with patients first.”

“This year has been particularly challenging due to product changes.”

“Allocations to trusts have sometimes changed mid-year, creating operational challenges.”

“When switching isn’t patient-led or clinically justified it creates challenges for staff and patients.”

“The impact on nursing teams implementing changes.”

“Difficult for patients to move between products.”

“Switching based solely on cost-effectiveness is problematic.”

Analysis

The major themes identified were**:**

1. **Loss of clinical autonomy and patient choice.** This was the strongest theme. HCPs emphasise that clinical judgement must remain the basis for therapy decisions.
2. **Impact on patients.** HCPs describe significant psychological, practical, and clinical consequences for patients, including anxiety and stress when forced to change a therapy that works, reduced trust in clinicians and the system, the potential for lower adherence/compliance after switches and confusion when products differ in administration method (e.g., pre-filled syringes vs pumps).
3. **Operational and workforce burden.** Switching is described as time-consuming, resource-intensive, and poorly understood by policymakers, creating an additional operational and workforce burden for HCPs. The workload included retraining patients and families, increased clinic appointments, communication workload, dealing with home care logistics and repeated switches due to supply fluctuations.
4. **Cost-saving claims.** Some respondents viewed the cost-saving claims as flawed. The economic rationale behind mandated switches did not include hidden costs such as training, clinic time, dealing with homecare changes, UK plasma collection costs and downstream costs through reduced adherence or complications caused by switching. The call was for reassessing economic modelling to include true system costs.
5. **Need for better engagement, consultation and data.** Requests include more stakeholder engagement, better consultation before changes, collecting PREMs, PROMs, and adverse event data before/after switches.
6. **Supply Instability & System-Level Concerns.** Many respondents argue that the current approach does not improve supply resilience, and in some cases worsens it. Concerns included artificially limited product lists, mid-year allocation changes and lack of robust outcomes monitoring.

Ends