

PID UK - The provision of immunoglobulin Patient survey

The aim of the patient survey was to learn more about the PID community's views on patient choice of IG products, price considerations and acceptability and willingness to switch. It targeted people who were receiving immunoglobulin therapy or who cared for someone with a PID.

The survey was open for one month from December 2017. It was made available via facebook, PID UK's newsletter and an emailed member invitation. The results of the survey have been circulated to NHS England Immunology and Allergy Clinical Reference Group and NHS England commissioners.

PID UK would like to thank all the participants for taking time to respond to this survey.

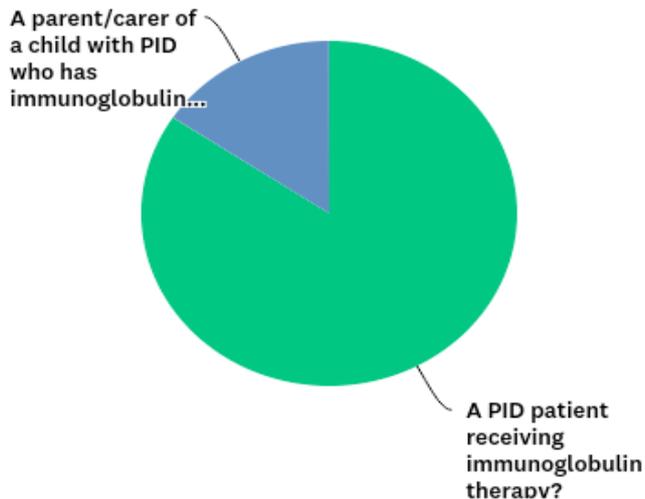
<u>Result sections</u>	Page
1. About the participants	2
2. Exploring the issues of:	2
• Patient choice	
• Acceptability of switching	3
• Importance of IG management system	4
• Influence of cost considerations	4
3. Extent of switching	5
○ Free text comments on reasons	5 - 9
4. Free text views on the provision of immunoglobulin therapy at centres	9 -16

Survey results

Section 1. Who participated?

238 people took part in the survey.

Q1 Are you:



224 responses:

PID patient – 84%

Parent/carer – 16%

Section 2: Participants were asked to indicate the extent to which they agreed or disagreed with statements concerning various aspects of IG provision.

Each figure gives the number of responses for each category.

PATIENT CHOICE

Q. Is patient choice an important aspect of providing IG therapy to patients?

Results

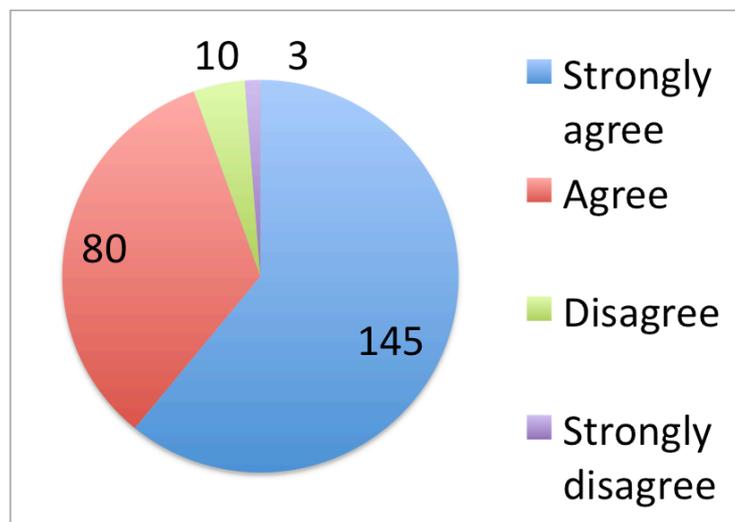
238 responses

Strongly agree – 61%

Agree – 34%

Disagree – 4%

Strongly disagree – 1%



Q. Patients should have access to a wide range of IG products so that their treatment can be individualised?

Results

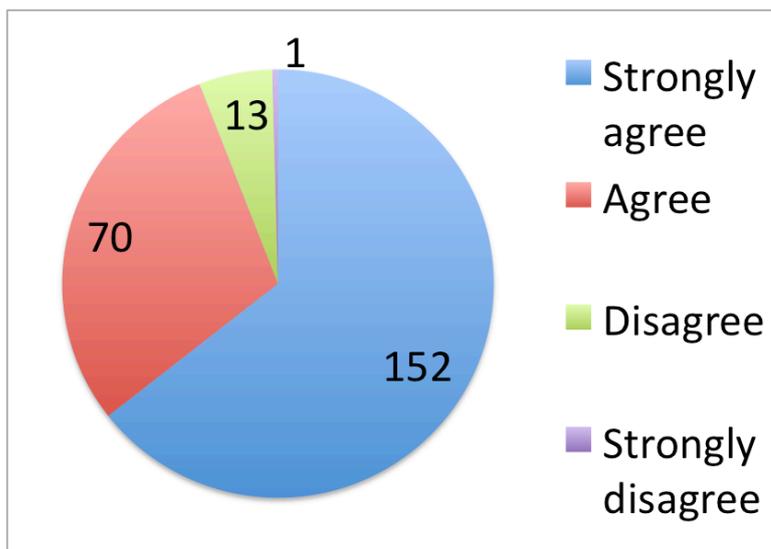
236 responses

Strongly agree – 64%

Agree – 30%

Disagree – 5.5%

Strongly disagree – 0.5%



Q. Newly diagnosed patients should have a more restricted choice of IG products compared to existing patients?

Results

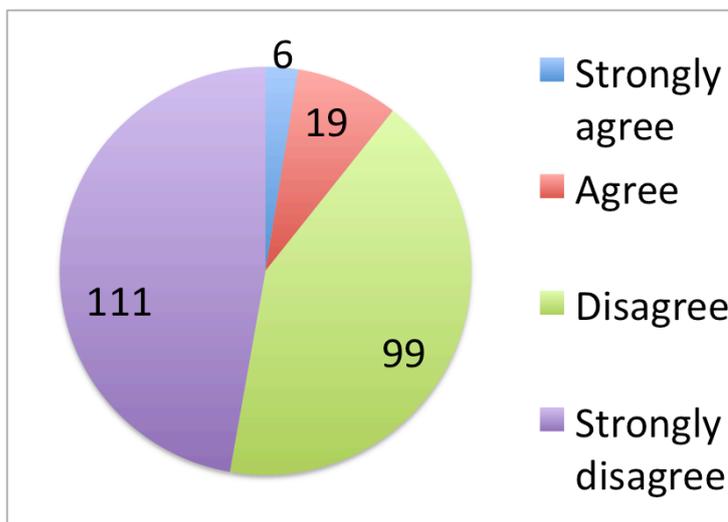
235 responses

Strongly agree – 3%

Agree – 8%

Disagree – 42%

Strongly disagree – 47%



ACCEPTABILITY OF SWITCHING

Q. It is acceptable to switch patients from one IG product to another for non-clinical reasons?

Note this excludes situations where a particular IG product is not available due to commercial reasons or batch contamination.

Results

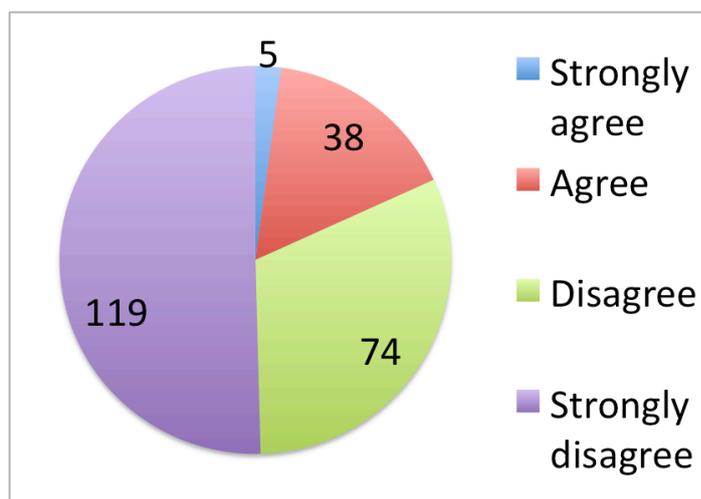
236 responses

Strongly agree – 2%

Agree – 16%

Disagree – 32%

Strongly disagree – 47%



IMPORTANCE OF IMMUNOGLOBULIN MANAGEMENT SYSTEM

Q. An immunoglobulin management system should ensure a secure, stable supply of a range of IG products for PID patients?

Results

236 responses

Strongly agree – 72%

Agree – 26%

Disagree – <2%

Strongly disagree – <1%

INFLUENCE OF COST CONSIDERATIONS

Q. The cost of an IG product should be a driving factor in determining what products are made available to patients?

Results

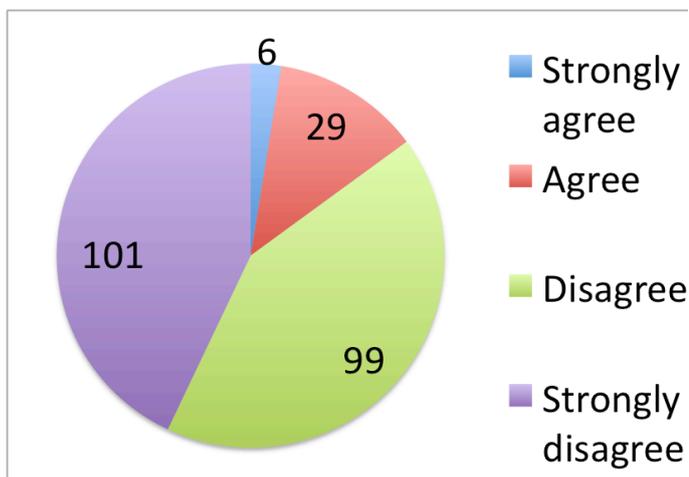
234 responses

Strongly agree – 3%

Agree – 12%

Disagree – 43%

Strongly disagree – 42%



Q. Patients should be switched from one product to another based on the cost of a particular product at any one time?

Results

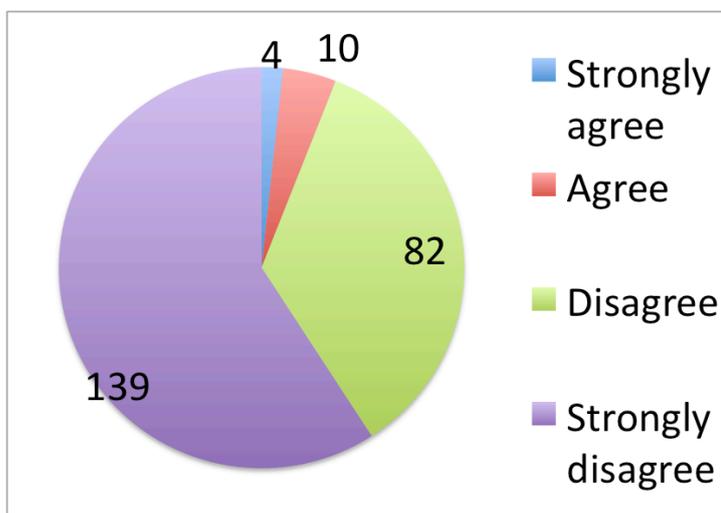
235 responses

Strongly agree – 2%

Agree – 4%

Disagree – 35%

Strongly disagree – 59%



Q. I would be willing to change IG products if asked by my centre if a cheaper, equally effective product was offered?

Results

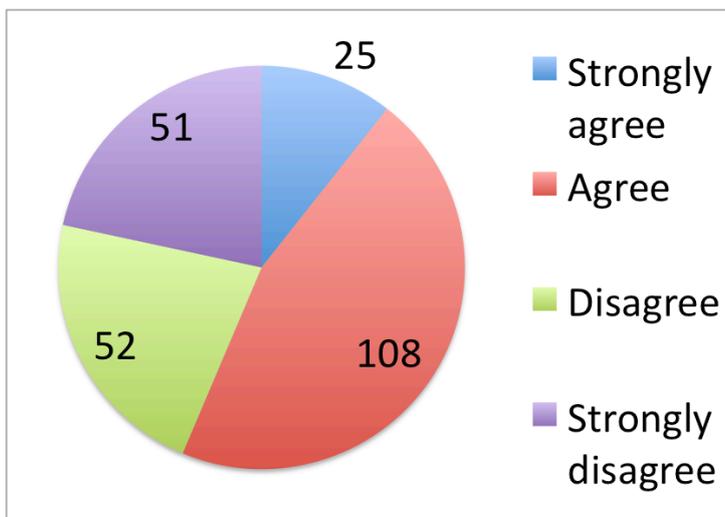
236 responses

Strongly agree – 11%

Agree – 46%

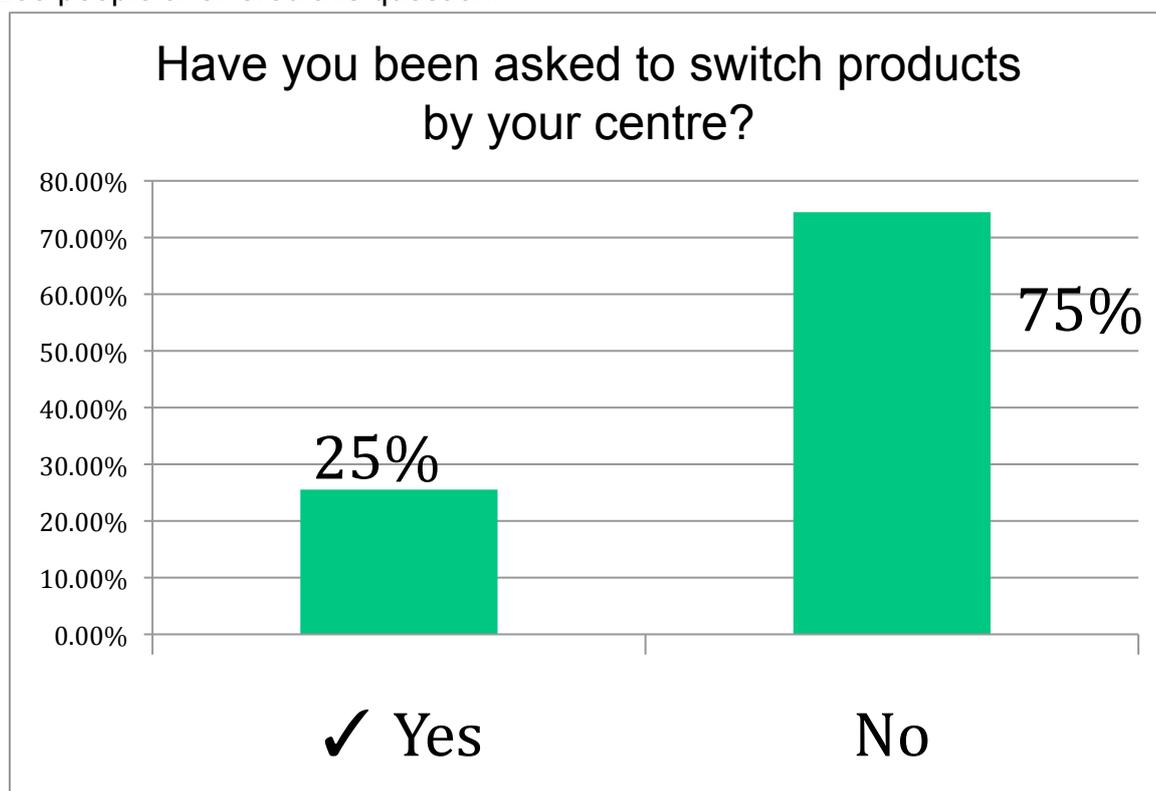
Disagree – 22%

Strongly disagree – 21%



Section 3: Extent of switching

235 people answered this question.



Free text responses received – *these have not been corrected for spelling mistakes etc.*

I would like to comment that due to the manufacturing differences between the different immunoglobulins I believe it is hard for hospitals to prove that one product is exactly the same and thus as effective as another product. In addition due to the time and effort that is required in switching between products for the patient and staff I think this should also be factored for cost and mental wellbeing of the patient. If a product works for a patient then I feel it is unethical for the patient to be switched to a different product due to cost!

Have switched once in 8 years. No reason given but substituted product was much easier to manage as it didn't have to be kept in a fridge.

Have received a letter from the local health authority that states in the future I may be changed to a different product due to cost etc but I haven't been changed yet.

I was asked to switch products recently due to a price increase of the product I had been using for 10 months. I was assured that should the new product not suit then I could revert to the original. I have been receiving IVIG for 23 years and have changed product a couple of times in that period. I don't remember the reasons for the first change but it was from sandoglobulin to flebogamma and I think this was due to improvements in the product as the sandoglobulin was a freeze-dried product that needed to be reconstituted but the flebogamma did not. Several years ago I was changed from flebogamma to privigen. My understanding was that was due again to improvements in the product. Privigen has been an improvement. There may have been issues with commercial availability but I don't know the details of this and there were improvements/advancements in product each time.

When moving from south east England to the West Midlands I was able to keep the same product though I had to change everything else including the pumps I used for my subcutaneous infusions. It is more tedious and I miss my old pumps. I have been informed that the change was due to costs and the area that I know live in.

I was switched at last session without being actually asked. I am not entirely sure of reason -could have been unavailability. Blood was taken to check in future of efficacy of product used!

I have been receiving IVIG for 23 years and have changed product a couple of times in that period. I don't remember the reasons for the first change but it was from sandoglobulin to flebogamma and I think this was due to improvements in the product as the sandoglobulin was a freeze-dried product that needed to be reconstituted but the flebogamma did not. Several years ago I was changed from flebogamma to privigen. My understanding was that was due again to improvements in the product. Privigen has been an improvement. There may have been issues with commercial availability but I don't know the details of this and there were improvements/advancements in product each time.

don't think ever been down to cost but over years have been switched occasionally when product not available or for possible safety concerns

I have received a letter saying I have to change, but this has not been fully explained to me. I believe that the switch is due to financial reasons.

Switched over the years, because products have become unavailable, switched from IVIG to SCIG to try and remedy issues(failed), switching back at my request.

product was no longer available

Subcuvia no longer available

Eventually no longer being produced and cost is getting to high

I couldn't tolerate privigen via iv

Product no longer available

I was just deotchedveithout notice because if price,

A number of years ago to try to reduce side-effects

I was switched to a more concentrated product because infusions would be quicker, but quite often infusion time is negatively affected by waiting for a bottle change or an air bleed.

Not yet. Newly diagnosed. Just started treatment this month.

I had a reaction around injection sites

Although I have been advised this could happen in the future

Cost of product

I was experiencing ascetic meningitis with privigen iv, so I was asked to change onto Cuvitru subcut

I have been asked to switch Vigam due to it being no longer available.

Product will no longer be available

well, I wasn't really asked - there was no choice as supply of 1 product had been withdrawn

Change from intravenous to sub-cut treatment.

Not yet, I am expecting to discuss at my January appointment though.

Three times because First time product being withdrawn in this country. Second to switch to subcut Third switch to a different subcut immunoglobulin

Product no longer available

Due to prior product no longer being available

No longer being commercially available .

Cost

Product Availability issues

no longer available but since I had reactions to a previous product, this was disappointing and time consuming

This was due to the product no longer being available.

I was switched from vivaglobin to hizentra for cost reasons. I was on hizentra for several years before I was switched to sub cuvia due to side effects with hizentra. I think patients should be started on the cheapest product and then their treatment tailored from there depending on clinical response and side effects. I think it's completely acceptable to switch to another product if a cheaper IG becomes available.

I have been informed by my immunologists that the Subcuvia product I use will be phased out over the next 12 months and hence I will need to change. However, due to the recent publicity over the proposed changes/guidelines for IG therapy, I wonder if this was indeed a smokescreen for notifying me that I would have to change rather than due to availability of the product.

Was told might have to come off subgam, but then was told as I was already on and doing well with it I could continue it did cause a worry.

I have been forced to change due to the fact that they are no longer manufacturing the IVIG that I was using but what I have been moved to is purely based on a deal that has been struck by the local health authority with a French company to guarantee a supply (at a set price) for their patients. Unless, that is Brexit alters this.

Because my treatment centre changed from royal Free to Southampton. Royal Free advised against the change and happily southampton agreed to keep me on same produce.

Only on 2nd week so unfair to comment - only given one choice - Civtruic?

The product was no longer available.

At a previous centre I was changed not sure of real reason and subsequent products caused reaction

Was told by immunology that I'm switching product I'm currently on subcut but yet to start the new product as been told nothing.

I was on Flebogamma 5% and was switch to hizentra subcut

I require a large dose, and the new product is available in larger volume bottles making the home storage and set up time more manageable

so far as I know, my grandson (2 and a half years old) has not been asked to switch

No longer available commercially

I went from privogen intravenous immunoglobulin to subcutaneous Gammanorm because my veins were difficult to access.

Product no longer available. This was a few years ago.

My original product was no longer available

They have mentioned that the cost is being debated

Due to the cost of the product

Not yet but am due in clinic in a couple of weeks time

Product no longer available

We weren't actually told it was being swapped. They just did it. They didn't give a reason until we complained and they said it was cost reasons

Haven't been asked, been told I'm switching in the new year. Emailed and am still waiting for an answer

I have been told the they are no longer making my product.

Apparently stopping August 2018. But don't know why

I have just switched but only because gone from subcutaneous to port iv as no fat or veins available for other methods.

This was for sound clinical grounds and I had no problem agreeing to it. The first dose was done at the centre I go to to make sure there was no adverse reactions.

It has been suggested that I switch to daily pushing from subcut as my product has apparently stopped being produced. This does not suit my lifestyle, which involves travelling extensively for work.

Re the last question which I did not tick a box.....the switch should be not just cost but faer more importantly to understand the quality of the product and that quality should be the same or better ,

I have been sent a letter that this is going to be the case

I have been asked to switch for various reasons: sometimes to fulfill a research obligation which presumably generates income for my service provider; at other times because a product was no longer available; at others because a product that would be quicker to infuse had become available and once when I had a reaction to a product that I had been on for some time.

I have not been asked to switch products, but I have been informed that my supplier may be switched. It hasn't happened yet.

Changed from IV to sub-cut. otherwise not yet although warned that it is coming

I didn't "tolerate" my first product (flebogamma) too well, i was switched to gamunex which has both been much better tolerated by myself and has also reduced infusion time.

However, I have been taken off my infusions and nothing can convince me it is not about the money, I have been really ill since an my immunologist refuses to put me back on, I know of a few patients in the same boat

Vigam running out. Not yet switched

I am switching products tomorrow due to slight localised reaction round injection sites and itching I don't know what product I'm going on to I was on subgam

Due to the discontinuing of subcvia

Subcvia I have been told is to be discounted. I was told October 2018. I am Now being told I have to change over ASAP as it is going quicker than expected

N/A my dad's meds we're switched with no warning 12 months ago with no warning or explanation. He's deteriorating.

Section 4. FREE TEXT ANSWERS – *these have not been corrected for spelling mistakes etc.*

Views on the provision of immunoglobulin therapy at centres

Hi there, I've been having immunoglobulin replacement therapy for 15 years now. I started in ivig and was moved onto scig about 12 years ago. I was also caught up in the CJD scare a few years ago. When we were assured all products now come from the USA as they are safer and that we were assured sufficient supplies so as never to run low of the Subgam I use. This new ruling is very worrying to me and my family after being caught up in a serious health scare previously

We are fairly newly diagnosed but would be really upset at the prospect of having to change immunoglobulin products. Our child has enough appointments, medications and complications to deal with and worry about without having to potentially have to go back into hospital to trial something new which could have side effects.

The system has worked so well for a long time - to make sure that patients can continue to have a make of Ig that suits the individual. Over time costs change so to take a short-term view is unnecessary.

Treatment should be provided as cost effectively as possible without sacrificing the care or quality of life of the patient. Life factors should be primary over any cost saving measures that can be implemented

I am entirely happy with the way that my immunoglobulin therapy is provided to me. I was happy to accept the recent change in product because of cost because I was assured that the new product would not adversely affect me in any way. As a patient, I am willing to take the advice of the professionals at my centre because I don't have sufficient knowledge on this very specialist subject. For me, it is nonsense to say I must be able to exercise patient choice.

A change in therapy products should have to do with patients health requirements and not related to cost of the product. Costs keep changing depending on availability of similar products in the market. What is cheaper today may be more expensive next year.

The immunoglobulin chosen for me was based on allergies and other health issues and I currently have very few side effects during/after treatment. I think the cost of dealing with adverse side effects , whilst perhaps a "hidden" cost could end up costing more and puts vulnerable patients at greater risk of additional health issues.

Trouble with everyone who self administers at home switching to a cheaper product is that we would all have to go in at least once for infusion to ensure we had no reaction. Not sure the hospital could cope with us all going in at the same time.

I would be worried that I may have a reaction if I had to change my immunoglobulin and would I need to change each year or every time the costing of each one changed.

It should be based on what is compatible rather than how much it costs

I feel very privileged to have immunoglobulin therapy which has kept me well since the start. Although I feel that the cost of the product should not be the prime driver for prescribing a particular brand, I was happy to try the cheaper alternative and so far, this is going well. I have trust in the medical staff at my centre and feel that they want to offer the best possible product and service for patients.

I strongly feel that immunoglobulin therapy & the products involved, should be based purely on clinical need & not cost. It is appreciated that cost effectiveness should be sought, where appropriate but must be balanced against 'best clinical practice for the individual concerned, at the time' ! it would be very unwise, based on recent experiences & knowledge gained regarding 'contaminated blood products' for the NHS to reduce the bandwidth of supply & restrict products based purely on cost effectiveness & not clinical need! It should be expected, that newly diagnosed patients, should have the same opportunities of product availability, based on clinical need, that I am currently receiving ! As there is a wide range of PID / PAD conditions, it makes sense that a variety of products are available, as we are all aware not everyone, conforms to a common treatment model, especially when ones immune system is involved !! When I requested, information on the yearly cost of my treatment, my Consultant initially did not want to divulge a figure, however... they put it to me in terms that the cost of my yearly treatment would easily be, blown in a week or two as a hospital inpatient & within a few days of ITU treatment (a likely outcome with my PID, if I was not on the appropriate treatment). Its a no brainer to give the appropriate treatment based on clinical need, even from a 'bean counters' point of view, never mind the fact that IGG Rx saves lives, improves quality of life & can often allow individuals to be productive members of society (for the bean counters) !

This is a vital therapy, without which I (and many others) would put much greater strain on the NHS. Whilst I agree that supplies of immunoglobulin should be sourced in an economical manner, the impact of different products on patients must be assessed carefully before changes are made. There is a risk of being held to ransom by a small group of suppliers who can increase the cost of the product.

I feel incredibly privileged to be given the treatment that I am given. I would hate for my treatment to be a financial burden on the NHS. If there is an alternative IG product available for me with no noted side effects, then I would happily switch products to save our health service vital funds.

I would not mind a change if asked first and there were reassurances as to its effectiveness, safety etc. I would however be extremely annoyed if changes were every few months on a cost driven basis. Continuity of care, safety and supply should be paramount.

I have been on my current therapy for 10 years. I understand I would have to change if the product became unavailable, but would not wish to change if it was for any other reason, as it has kept me well for so long. As I have to travel a far distance to see my immunologists, home therapy has worked for me. I assume that changing the product due to cost etc, would probably mean I would need to visit the hospital more often for supervised alterations to my treatment.

It would seem logical to link cost of the product to the quality/effectiveness of the product ie a more expensive product is likely to be more effective. If it can be proven that a cheaper alternative, is in fact as effective as the more expensive product, then I don't necessarily have an issue with changing. However given that the medication I currently use is effective and that my last change in medication resulted in two weeks of extreme discomfort, I don't currently have the time or the wish to risk suffering this again.

I have felt pressurised to change when product was harder to source esp as need it in 15 g quantities not 20g Luckily I am still on product and correct quantity at present

I've had IVIG at several different centres over the past 7 years, in England, Wales and Scotland and have always been on the same product (Privigen) as it has worked fine without any major side effects. I know how having Privigen affects me and the exact highest rate that I can tolerate without side effects. Whilst I would be fine with switching to a different product if asked, I would like to think that it would be of my own choice and the switch would be appropriately managed (i.e being given the time to find out what rate I am OK with) rather than it being rushed. I recognise that the NHS is under continuing financial pressures, having previously worked for it. Therefore whilst it should be able to offer a wide range of treatments, it can't be a universal pancea and should therefore not fund some particular IG products as primary options on cost grounds if the manufacturer is unable to offer it at a

reasonable price compared to other equally efficacious treatments. If a person is unable to tolerate other products though, then they should be offered other 2nd line IG products, even if they are more expensive, as it will ultimately probably end up costing much less compared to the patient having a hospital stay if their treatment is ineffective.

it should not be about the cost, but about the product which is safe for the individual patient and the well being of the patient.

Being asked to change immunoglobulin just because of cost is not acceptable.

I feel lucky that decisions about method of delivery and immunoglobulin product have involved me and my preferences. Regular, lifelong immunoglobulin therapy is a big part of a person's life and having it in a way that best fits their life and having a product that they feel comfortable and safe receiving are very important for overall health and well-being.

Have always been happy to follow advice of the experts at my centre. Would not wish to see this advice constrained by cost or commercial pressures.

Treatment has always been provided on an individual basis and only changed in an effort to improve the patient's quality of life. It is imperative that this continues

It's vital that the correct product is available for the individual patient, it might be a few extra pounds to the government but it can mean the difference between a good and a poor quality of life, and when it's an 11yr old girl that is in question with her whole life in front of her, surely that must mean something. Thank u.

It is & should be respected for/as being life saving treatment. PID patients already have so much to cope with, without the huge anxiety of whether their particular treatment is/will continue to be available to them.

Have only been on immunoglobulin therapy for 18 months, so not an experienced patient, cannot judge whether switching is a good or bad idea.

I have suffered a lot from adverse reactions especially with IVIG, and they have been very helpful in switching products and finally switching over to SCIG. Although I am aware that there are many different options, but they seem to have a 1st line, 2nd line etc that they follow, rather than providing patients with all the information up front. I suspect this may be related to cost.

The provision at my centre has been good with no suggestions about swapping products (that I am aware of). Patients need to feel that their well-being takes precedence over cost.

I am extremely happy with the care I receive from my immunology team. I found the original email and this survey rather disturbing. Not because my product may be changed as I completely trust my team but because it has the capacity to worry and upset people who may not fully understand the process for funding these products. The NHS does not have a bottomless pit of money. I trust my team to provide safe treatment to me which successfully treats my condition but I understand NHS England has to get a good deal too. If I had to buy this product and 2 products had the same safety and side effect profile I would choose the cheapest. I have completed the survey but an agree or disagree reply was not really appropriate for some of the questions.

Having a son who has a genetic condition where he doesn't produce anti bodies and relies on this treatment this would be devastating for him and the quality of his life .. he needs this in order to live and be healthy .. it is very important that my son is kept on the treatment he receives to reduce chances of reaction or using a different pool of donors from the one he is established on .. to think this would not be available for my son or that he would be restricted on this is incredibly stressful and doesn't bear thinking about .. he is only 11 months and needs this to survive ... I hope this situation will be resolved and that he will be able to access the treatment not based on cost but what is the best treatment programme to ensure he will be healthy and live .. this is my child's life and this must be taken into consideration as to how this treatment is providing a life line to patients . This is a basic duty of care .. if a patient has been on a certain treatment on a long term basis and it has proved effective surely it can't be correct that this would change merely based on cost .. also to restrict products would surely have the result of treatments potentially going short and this is most definitely not something that we could risk happening to our child

At the moment I feel confident that my immunologist would only change my product if it was in my best interest.

I have left some of these questions unanswered as the framing of the question potentially leads to a biased response. For example the question 'patients should be switched from one product to another based on cost?' has many potential factors behind it. If, for example, by limiting the cost of products, this would produce a downward pressure upon drug companies to reduce their cut/profits on this very expensive product, then my answer might be 'Agree'. If by limiting cost it would stop constant reinvention of the same product but keep an effective range that is

'good enough', meaning that funds might be available to develop treatments for aspects of PID that are not treated by immunoglobulin, then, again, I might agree. Similarly, if by limiting the range of products to newly diagnosed patients, more people could receive good enough treatment rather than some a 'Rolls Royce' and others nothing: then my answer would be different. There are numerous nuances that these questions do not address and I'd need to see more strategic background to be able to give an informed response based upon my experience as a patient. I fear a commissioner would drive a bus through the gaps in the survey!

To date, I have always been given choices about my treatment. I wouldn't be strongly opposed to making a change as long as the product efficacy and delivery is acceptable.

I have been using IG therapy for over 10 years, and my health has been so much better. However, I am always been made aware of possible allergic reactions when using the therapy, so I would be anxious about regular changes to the treatment in case this happened. If I was to be put in a position of repeated change, I would have to travel to the Immunology clinic (over an hour's journey) for supervision more often, which would involve my husband taking time off work to be with me. I understand the need for change if the product becomes unavailable, but not if it is down to a cost factor, as whilst on this therapy I have avoided in-patient stays over the 10 years, whereas before the therapy I was admitted on a regular and certainly on an annual basis for infections and operations.

I have excellent treatment. I have been on the same product for 7 yrs & would not be happy to change at all. When you find out you have this condition & need this treatment it's very frightening & life changing. It take a long time to adjust, you always have concerns about side effects etc. When patients are using a product that suits them with little side effects, leave them alone to continue.

This is a blood product which is a different scenario from changing a patient from a branded to a generic but identical product. I am receiving steroids with my IV product to help me cope with side effects and I am very worried about a switch which might leave me feeling very ill every 3 weeks. A wide range of products means that we are protected against one product suddenly being unavailable. The impact on the patient's health and the cost of changing sub cut patients needs to be factored in as they would all have to be brought into a hospital to be monitored in case of anaphylactic shock. I realise that the NHS is having huge problems because of underfunding. But sick PID patients needing hospitalisation will put an even greater burden on hospitals.

As a PID patient using subcutaneous infusion at home, I am honoured to feel part of a partnership with the hospital, clinical team, GP & immunoglobulin supplier. However, this partnership is founded upon respect for the professionalism of my clinical team, mutual honesty and openness - the prime focus of which is my ongoing health & wellbeing. Whilst I recognise the importance of ongoing product monitoring & cost effectiveness/value for money, I would hope that any decisions made concerning a change to medication would take due consideration of all related issues & the opinions of my clinical team. Thank you

I was the first person at my centre to be trained in how to do Ig subcut at home and that has been very useful and saves the hospital an outpatient place as well. All equipment and the Ig (Hizentra) are delivered and I get a visit from the nurses just to check on things every now and then. I fill in a form for each subcut I do, and stick the label from the bottle onto it, so they can identify any issues with a dose. I have to notify them in event of ill health and send eg a phlegm specimen. I believe they are now training up a few more people. I had no problem with the IV delivery before the subcut. I moved from the main centre to my local hospital (Northampton), once they had stabilised my Ig levels which was more convenient. I am still monitored by the main centre in Leicester.

Price should be the last consideration for patients. It should be about individual needs and quality of care. I actually found the questions in this survey quite offensive, they were all about money and the patient was just an afterthought.

Have heard that some people have been asked to change immunoglobulin based on costs. Have previously had a bad reaction to one particular brand and had to change to find a more suitable brand. So I would be very concerned about changes being made based on price rather than clinical decisions.

So far it has been excellent with the products being chosen to deal with my anti IgA antibody response.

Fantastic but am always concerned that will have to go back on IV immunoglobulin due to cost of sub cut immunoglobulin - have to justify treatment by demonstrating a reduction in hospital admissions for infection - which means I put off attending until I absolutely have no other choice

I feel that people are being told they will stop immunoglobulin therapy to save money, rather than the patients best interest being taken into consideration.

I was only informed a month before I ran out of my current home therapy supply that I'd no longer be able to use Viagam. I didn't have much time to consider my options... if indeed I had any!

At present I have not heard of this apart from yourselves notifying me. I would be very upset if things change, it's taken over a year to adapt to the regime I'm on, even now there are upsets, To be changed about due to cost is unacceptable, I have done nothing to have this condition, I need this for my quality of life....I am upset that this is being threatened with change.

I know that some products have been discontinued. My centre have said that they like patients to be on a range of products so that if there is a shortage of a product, not all the patients are directly impacted in one go.

I've always been given good care. I find IG kind of like paracetamol, I don't care if it's Tesco's or Asda's own brand as long as it works!

My provision of immunoglobulin therapy has been excellent. I was one of the first patients offered to trial human hyaluronidase which allows the skin to absorb more immunoglobulin and at a faster rate. This allows me to infuse at only one site now and in a shorter time scale. I believe this is only available in Wales as it more expensive, however the benefit to me as a patient is invaluable and should be offered to all patients irrespective of post code or country.

I prefer to stay on the same Immunoglobulin treatment because it is working well for me. I have only had to change product when moving from IV to Subcut.

I really don't care which immunoglobulin I am on as long as it is effective. I have switched previously due to a previous brand not being as effective/ side effects. As long as it works I don't mind

The provision of immunoglobulin therapy has been great. Thirteen years of staying out of Hospital which has save the NHS loads of money and enabled me to study and work. With out this provision I would probably not be here or if I was I would be in a very unhealthy position.

Would be very worried if asked to change as current product works well and doesn't cause any upset.

I get my supplies delivered to my door, by Lloyds pharmacy. The product choice is driven by my immunology team

I am a Papworth patient and Lloyd's provide my immunoglobulin. I have been very happy with how efficient and helpful both have been.

I rely on the expertise of my consultant to offer the product that he/she feels is most appropriate for my condition after reviewing tests and symptoms.

some issues around bottle sizes when you require 15g not 20g to be infused

throughout my treatment over the last couple of years, there has always seemed to be financial pressure on the department, which has always clouded the amazing work provided by the immunology team

My centre is fighting to keep my son on hizentra

Have used to providers and both have been excellent. My daughter is at boarding school three hours away so there are sometimes issues that need sorting out. Everybody always very helpful.

Great treatment at Heartlands hospital Birmingham

My sons have weekly Home therapy Hizenta which seems to be working for them

City hospital are amazing always keep up to date

So far so good although the consultant says I could do with more but hasn't increased my dose. I currently have 45g of Privigen I.V. every 2 weeks and I now have the added bonus of being diagnosed with Evan's Syndrome.

I have no problem

I think I have an excellent service.

Generally it's a very good experience, but it depends heavily on the skills of each individual nurse.

I've had a good experience so far. Newly diagnosed, just started treatment this month. Health care at home delivered no problem except for missing my sharps bin at first and my clinical team have been very helpful.

Very good care and management of my PID.

Cannot be more grateful for the care and efficiency I experience at the hospital, or that I have been offered the treatment in their place

As a patient from wales I feel we are well supported by our hospital team.

the Oxford JR centre are excellent - I have no idea how my treatment could be improved, as I have to assume they are doing the right thing for me!!

need more staff.

We could do with a personal unit, at the moment we have to share. Also more office space for our medical professionals, they are squeezing into the tiniest space UHWales

There doesn't seem to be much communication between patients and specialists regarding products available. I've been told so many conflicting reports regarding the availability/supply of the current product I am on which makes me nervous.

Very good

There needs to be greater protection of people with rare diseases. Its easy to feel they are not taken as seriously as people with more common problems.

No problems for 13 years on subcuvia BUT I'm concerned this product will become unavailable & I have no side effects on this 80 ml weekly!!!

I hope I can stay on the same one now,as I don't want to change again after 4 months starting this new one.

After 3 years on Gammanorm my treatment was stopped as it wasn't felt the results were cost effective.

Has been trouble free and exceptionally efficient

Currently no complaints

Team are fantastic. They seem frustrated by this new aspect of receiving meds.

Lacking - I haven't been reviewed since starting it nearly two years ago.

Feel left and abandoned at times. My immunoglobulin hasn't improved yet and I've been on the stuff since July but just left to fight infections alone. I feel they don't care about me, my situation or my health!

The provision my daughter received IN cardiff is outstanding. They are so understanding, compassionate and accomodating and they do what is best for all individual patients and their circumstances at the time.

So far so good

Yet to be used

I would recommend a more holistic approach from centres for patients with Immune deficiencies e.g. gut health probiotics supplied to patients due to taking antibiotics; recommended supplements (A MORE HOLISTIC APPROACH)

Just had my regular treatment postponed because pharmacy could not get hold of the new product that I have just been switched on to. Is this going to become a regular occurrence?

I would be worried to change from a product that works well to another one..

Sometimes my treatment is delayed because of shortages, or the pharmacy have not ordered it from the manufacturer very annoying.

Currently I am under no pressure at all to change the product that suits my condition

I've only just started so I've never had to change my immunoglobulin, I've never had any problems and I feel I would be happy with whatever my healthcare provider suggested as long as it wouldn't cause any adverse effects.

Leave well enough alone my centre "Elliot Dines" RGH have managed my condition for 20+ years and i would like it to stay exactly as it is.

Acceptable

switched to Hizentra this year. Switch went well with support from LRI team

i havent been asked to change and i hope i dont get changed without a trial run of the product as i had side effects from one product

I am treated at Graham Hayton a unit at The Royal London hospital. I cannot praise them enough for the way they look after me. They are friendly yet so professional. They are always on hand to answer questions I have or worries that I may have about illness. I am so grateful to be treated by them.

I am on home treatment so only go to my hospital to pick up my supplies.

currently not given a range of choice.

Drug calculation because they are different %

So far it is appears very patient led.

So far so good

As I understand newly released guidance a driver for changing IG medications is to be cost driven. I don't agree with this. The reasons should be clinically driven and on the basis of what a clinician thinks is best for their patient.

switching product could endanger the lives of PID patients. if a patient gets an infection due to IG being less effective (when the previous IG did prevent infections) this could have serious consequences. changing product when it is not necessary can also increase the risk of a severe reaction to the product.

We have issues with supply of subgam, often having only part of the delivery dispatched and on one occasion none was available

I have no issues at all with the Privigin product and the service to supply the products is excellent

JRH have been great

Why change a product that a child has been on for nearly 17 years with minimal hospital admissions which is saving NHS money - to possess Bly be asked to change product as he is approaching adulthood- and might have a detrimental affect on his health and cost NHS more with difficulties arising !

I didn't get a choice of product apart from IV or SC. I would change if a cheaper product was as effective.

Training in doing therapy at home was really good.

I have never had a problem. My contribution to society and the economy is far more than the cost of the immunoglobulin.

Absolutely excellent

An excellent service which is life-giving/

at the moment there is no issues of it being swapped

The provision has always been very well organised and I would be very anxious if changes started to happen based on price.

If you disagree with the doc she withholds the product

My centre is very good

It is good although had no choice of product

No problems at all

I do home therapy

Everyone's situation is different and I feel I don't know enough , medically ,to know how easy it is to change from one product to another or the effect it has on individual patients.

I think the NHS does the best job it can for us. What terrifies me is what happens when the NHS disappears....

ENDS