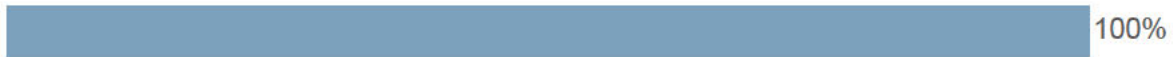


IP survey IP692_2

This report was generated on 27/03/24. Overall 17 respondents completed this questionnaire. The report has been filtered to show the responses for 'All Respondents'.

The following charts are restricted to the top 12 codes. Lists are restricted to the most recent 100 rows.

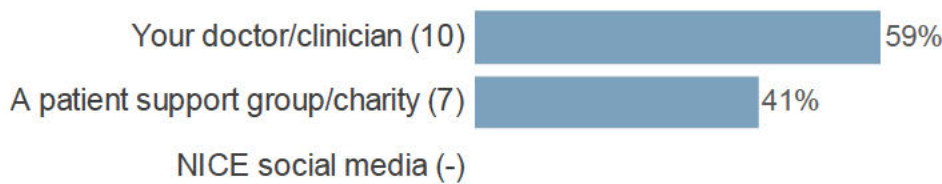
I have read the information above which explains the purpose of the project and how any information I provide will be used



I consent (agree) to NICE using the information I have given in the ways described above



How did you hear about this survey?



Other (please sepcify)

- From contact with [REDACTED]
- A friend who also has had the procedure carried out.
- Another patient informed me of your survey.
- From a person who has also had this procedure
- A friend who also has osseointegration.
- Prosthetist

Are you (the person completing the questionnaire):



Your age (in years)

Count	Sum	Mean	Sample Standard Deviation	Minimum	Maximum	Range
17	849	49.94	9.87	33	64	31

How long ago did you have the procedure?

April 2018	24	2 years
6 Years	18 months ago	2002 (22 years ago)
November 2022	6	2003

In years

Count	Sum	Mean	Sample Standard Deviation	Minimum	Maximum	Range
11	107	9.73	6.77	2	22	20

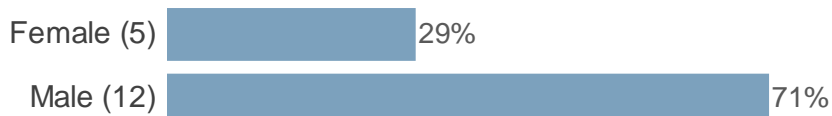
In months (OR In months)

Count	Sum	Mean	Sample Standard Deviation	Minimum	Maximum	Range
2	52	26	5.66	22	30	8

In months (OR In weeks)

Count	Sum	Mean	Sample Standard Deviation	Minimum	Maximum	Range
0	-	-	-	-	-	-

To which gender identity do you most identify?



Prefer not to say (-)

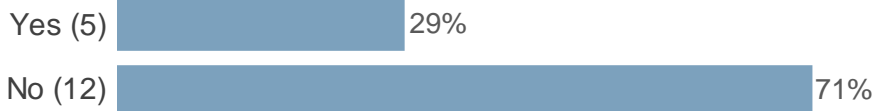
Did the procedure work?



If somewhat or no, please provide further details along with information about whether symptoms later reoccurred.

I had my first implant in 2003. I had 9 faultless years of mobility, freedom and happiness. In 2013 the pin snapped and the whole implant was removed a year later due to deep bone infection. I am now on my 3rd implant which has been successful but with some complications which I am working through currently. I have had good and bad with all the implants I have used.

Did you have any side-effects following your procedure?



If yes, please provide further details along with information about whether symptoms later reoccurred.

I fractured the neck of my femur 1 month post surgery, due to loss of bone density as it was 14 years post amputation when I had the implant fitted

Occasional soft tissue infection at stoma site

Bone infections which were treated with antibiotics, however I now have deep bone infection which can only be solved by the removal of the implant

The significant side effect I seem to be experiencing is loss of bone density. This loss in density is not limited to the implant site, so this could be due to other medical factors. The other side effect I have suffered is breaking my femur. I am aware that there are many femur breaks amongst our cohort. My low bone density may have contributed to my femur breaking.

Throughout rehab you have pains in the bone and also muscle soreness. After rehab is complete these subside. Infection causes pain and different symptoms depending on the infection type. There are not necessarily side effects unless there is a problem going on. With my current implant I have suffered with stoma pain which is not a pain that everyone experiences. Depends on the length of the residual limb and how much flesh is moving at the skin/bone/implant interface. Every patient is different and some experience pain and others don't. Some get re-occurring infections an some get none. '

How long did it take you to recover from the procedure?

6 weeks in total from Implant to being fully healed and back to wearing Prosthetics, my Surgery was done as a day case, and I was back home the same day, started re-hab and loading the very next day, and back to work by the second day, I had little or no pain, had no issues or side effects at all and considering I would only wear Prosthetics on special days and for short periods, I was 6 weeks after surgery, wearing Prosthesis all day every day, and still the same 5 years later.

What does 'recovery' mean? I was in hospital for 2 days after the surgery. Dressings continued for a few weeks. Full rehabilitation (going from load bearing twice a day, then walking with two crutches, then one crutch and finally no walking aids at all took about 5 months.

6 months post fracture I was fully walking again

3-4 months gradual weight bearing then walking without stick/s (mostly)

Minimal recovery time.

I would say about 8 to 10 months, before that I would still get muscle pains from walking or being strapped in to a sports chair.

I had the surgery on the 16th May 2022 and i was walking unaided by July 2022 and have not used any walking aid since

IP survey IP692_2

How long did it take you to recover from the procedure?

to be up and walking to my satisfaction took about a year

Approximately 6 months before I started training the leg for weightbearing. I was fully weightbearing after approximately 11 months.

Less than 2 months. Because my operation was done in conjunction with some plastic surgery, it was done in two phases spread over 4 weeks. It then took another month for me to get back to my normal walking routine.

6 weeks

6 months

4 weeks

1 year from first operation to walking

I started rehabilitating from my procedure within 24 hours of my operation. My procedure was done in two stages. First was the implant, and second was the skin graft around the site. I was up walking, free from bandages, within twelve weeks of my operation.

18 months from start to finish for first implant. Current implant was 6 months. The push fit implant has a much quicker rehab protocol.

How did the procedure positively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

Before surgery, I had such soft tissue loss, wearing prosthetics was painful, uncomfortable and caused skin rubbing and damage to such a degree, I could only wear them for a few hours and spent most of my life not wearing them at all, we could not get a socket to fit no matter how many times we tried, however, post surgery I wear prosthetics all day every day, it put on as I get out of bed, and only taken off when I go back to bed at night. This single surgery has changed my life for ever, I have significantly changed my life, the implant is so comfortable, you simply don't know it's there, I no longer have back issues from being mis-balanced, I have no pain and therefore take no pain relief, this gives you so much more energy and I no longer suffer from any fatigue. I can now use the prosthesis for so many functions that I was struggling with, I use the implant for driving, gearboxes, riding motorcycles, gardening and lots of other workshop procedures, It helps with domestic duties, cooking, cleaning etc, indeed, it has been life changing to say the least, the best thing I ever had done.

IP survey IP692_2

How did the procedure positively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
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Osseointegration has absolutely transformed my life for the better. I no longer have to endure skin breakdown and pain emanating from wearing a socket. My prosthetic leg does not become loose over the course of a day nor do I have to add extra socks to cover my stump to keep the leg secure which was unbearably hot and sweaty in the summer. It takes me seconds to don and doff my leg in comparison to about half an hour of cursing the socket because it was difficult to get it correctly aligned so the foot was at the right angle. I am able to wear my leg all day without a feeling of constriction and a need to take off my leg. I am able to walk more safely as I can feel the ground through my bone and feel the position of my leg. Previously I had to look in a mirror to know if I was putting equal weight on both legs and therefore standing straight without leaning to one side. I am able to walk easier without the socket impairing my movement, particularly up slopes and stairs. There is no lag and juddering of the prosthetic leg when I am changing direction and turning corners. I am able to ride a bike without the socket catching on the saddle of the bike with each rotation of the pedals. I feel much better about my appearance as I do not have a socket jutting out at my hip which was visible through clothes. Also, my clothes are no longer worn to a hole from the friction of the socket rubbing against them. I am also able to sit more comfortably as both my hips are level without one being raised higher than the other. I am also able to sit on hard surfaces such as toilet seats without sliding off. My range of movement is better because there is no socket to restrict me for instance when I am sitting on the floor with knees bent. All the above physical improvements have contributed to a better state of mind. I do not worry about going out and my leg becoming loose. As I am a transfemoral amputee this was a great worry for me previously because I did not want to have to remove items of clothing in a public place so as to re-attach my prosthetic leg. The osseointegration process has not only helped me but my family as well because previously we had to abandon walks midway and return home due to socket issues occurring. My improved confidence in my ability to be able to perform different functions has meant that others treat me more normally resulting in easier relationships with friends. Previously I was in a state of depression because I was an active individual prior to having an amputation due to trauma. Life in a socket was very different to my previous lifestyle. However, having had osseointegration my life now is much closer to the life I had prior to amputation and there are far fewer limitations. I am no longer in a state of depression and enjoy most of the activities that I was able to partake prior to amputation.

I had my right leg amputated above the knee in 2004. For the 6 years that followed I was using a prosthetic with a traditional socket. However in the last 3 years of that I was constantly having revisions to my stump in order to reduce the amount of pain I was experiencing whilst wearing a socket. This ultimately proved to be ineffective and in 2010 I decided that further surgery was not in my interest and I then transitioned to using a wheelchair or crutches for mobility. This had a massive impact on my social life, my mental health and in turn my general state of health. As I am a large man (195cm/~100kg) I was starting to experience shoulder pain and significant bruising/blistering to my hands as a result of using crutches and I was faced with a choice of either using crutches and experiencing physical pain but yet having greater mobility, or using my wheelchair and being limited on the choice of venue I could attend. This started to lead me down a very dark mental path as I could see no option for walking again. I heard about ██████████ in Jan/Feb 2018 and attended a clinic at ██████████ in Feb/March and then had the surgery at ██████████ in April 2018, having to max out all my available credit, remortgage my house and company in order to fund the surgery - but what choice did I have? Despite the fracture of my femur post surgery and needing to have a DHS installed - what has happened to in my life since then is just unbelievable. I am fully mobile, fully independent my mental health is back on track and I am pretty much walk without limits. My social circle is full and wholesome again - I can quite honestly and without hesitation say that OI is the second life changing event to happen in my life.

IP survey IP692_2

How did the procedure positively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
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- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

This procedure totally transforms my life both physically and mentally. I am unable to use a traditional prosthetic socket due to size of stump and deterioration of skin quality which meant I am unable to walk with two legs. Using crutches or wheelchair was the only alternative. This was very awkward and totally depressing, I was hating life to be totally honest. I did not really want to go out and socialise or do anything outside of the house. This obviously had a massive effect on my family and friends. I feel this procedure should be widely available on the NHS. I appreciate the high cost of it but if I could have afforded to go private and have it done sooner I would have. I am eternally grateful to the NHS and especially my clinical team at [REDACTED] for enabling me to have a life back. I am so very happy now and am enjoying my life to the fullest I can at my age and disability. The occasional soft tissue infection is a very very small annoyance and that is all.

Osseointegration changed my life for the better originally. Every activity, home or work, was easier and more enjoyable. My quality of life improved beyond my expectations and I undertook new activities that I thought were beyond myself whilst wearing a socket prosthesis resulting in a happy time of my life.

It has given me so much independence where I don't need to rely on anyone for most of my daily tasks. It gives me the ability to drop the wheelchair for the most part of the day and sitting with my family is more easier and convenient after the procedure.

I haven't used a day chair at all for the last 18 months, I now feel more confident going out, I can now go for family walks.

Osseo has improved my quality of life massively it has allowed me to be pain free for the first time in years and has allowed me to no longer require any form of walking aids or wheelchair use and has allowed me to return to full time work and regain my full independence. It has allowed me to become a hands on parent again and to be able to do everything I want to with my children. Mentally it has made things so much better as I now feel like myself again and feel like I am able to contribute to both home life and work too. This has been the best surgery I have ever had and I can not recommend it enough.

I had always struggled with using a socket which led to sores, blisters and the uncomfortableness of the socket itself even when sitting. Weight gain, weight loss and temperature especially heat all effected my ability to wear a prosthetic limb, having osseo is a game changer in my everyday ability to wear my leg without the trauma of not knowing if it would fit on any given day. This improved my self confidence, wellbeing and how I view myself. My goal after so many years using a socket were to be comfortable and this has been achieved.

My leg amputation left me with a very short residual limb. Normal sockets available did not work as they would not stay on my leg. The ones belted on were extremely unsafe and jeopardised my badly injured arm with risk of falling. I went 7 years without walking as a wheelchair/permanent crutches user which left me unable to do so many everyday tasks. Being a fiercely independent person this made me very sad at times. I had my first child on 1 leg and could not manage him independently as a toddler. I also couldn't do simple things such as push a trolley around a supermarket, walk up and down stairs, hold a handbag or any form of item on crutches, attend general work conferences without having to assess the venue beforehand, change a nappy in a public place as the changing tables are too high, etc. The list is massive! After osseointegration I had another child and was able to take both children to the park independently and push the pushchair around. This was life changing for me.

Osseointegration has made me much more mobile and independent than I would ever be without it. It has also enhanced my wellbeing as I do not get stared at or asked as many questions about my disability. It isn't without it's faults and I still can't do many things like running, lifting heavy objects or walking/standing for longer periods of time, but for me, the mobility I have gained would have never been possible, and it has enabled me to live life more normally.

IP survey IP692_2

How did the procedure positively affect your condition and/or your quality of life?**Please consider things such as:**

- Your physical symptoms
- Your ability to perform daily activities
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- The effect on family, friends and others

This operation was a game changer. The positive effects of this procedure include the following: reduced time presenting at prosthetics - no need for sockets. Increased time on my feet due to be able to simply attach my prosthesis. Increased mobility, being able to live an almost normal lifestyle with my prosthesis. My quality of life is increased due to my self reliance and independence. I am able to carry out most sporting activities less running. Having my independence has meant I am able to integrate back into the labour market, working full time as a civil servant. All these positive effects have meant my mental health and wellbeing are as good I can remember they've ever been.

Life is 100% better after OI. Having no sores and aches is probably the biggest advantage. Being able to cover any distance without issues is huge. Putting on the prosthetics is very simple and time saving.

Now able to walk with just one stick. Previously was in a wheelchair for 6 years. Daily activities easier. Able to access places previously not accessible increasing quality of life, lifestyle and social life. No effect on emotional health or wellbeing as was O.K. before.

The procedure has improved my quality of life from all aspects. Donning my prosthetic is quick and easy walking is more naturally and gone are the days of socket rub. I can sit anywhere without fear of losing suction. I feel more stable and confident enough to carry my baby grandson. Emotional I feel so much better in myself. I always had to work my day around my leg but now I barely give it a second thought.

What a fantastic procedure, it gives you back so much. No more sores, able to carry out daily activities with no pain, ease of mobility. Quality of life, lifestyle and social life. I have to say is 100% better. State of mind is back to normal as in before amputation. Family and friends can definitely see how much better you have changed

IP survey IP692_2

How did the procedure positively affect your condition and/or your quality of life?**Please consider things such as:**

- **Your physical symptoms**
- **Your ability to perform daily activities**
- **Your quality of life, lifestyle and/or social life**
- **Your state of mind, emotional health and/or wellbeing**
- **The effect on family, friends and others**

I have experienced several advantages since my Osseointegration surgery compared to traditional socket-based prosthetic systems. These advantages have significantly improved the quality of my life and functionality as an amputee. **Improved Comfort and Stability:** My implant is anchored directly to the bone bypassing the need for a socket, which often causes discomfort, skin irritation, and pressure sores. My direct skeletal attachment provides excellent stability and reduces the risk of prosthetic slippage or movement during use. **Enhanced Range of Motion:** My osseointegration affords a more natural range of motion than socket-based prosthesis. It provides a stable foundation for the prosthetic limb, enabling smoother and more fluid movements. **Increased Mobility and Functionality:** With improved stability and range of motion, my osseointegration enables me to engage in a broader range of activities with greater confidence and efficiency. This includes walking, climbing stairs, participating in sports and recreational activities, and all my personal care needs. **Better Proprioception:** My osseointegration restores a more natural connection between the residual limb and the prosthetic device, enhancing proprioception. My improved proprioception allows better control and coordination of my movements, leading to a more intuitive and responsive prosthetic experience. **Reduced Energy Expenditure:** My implant offers a more efficient and biomechanically sound interface with my body, reducing energy expenditure during everyday activities. This helps reduced fatigue and increased my endurance. **Enhanced Comfort and Hygiene:** My osseointegrated implant does not trap moisture or sweat against the skin, reducing the risk of skin irritation, infections, and unpleasant odours. This promotes better hygiene and overall comfort. **Simplified Prosthetic Management:** Osseointegrated prostheses eliminate the need for cumbersome socket fittings and liners, simplifying my prosthetic management process. Donning and doffing my prosthetic is now quicker and easier. I have also reduced the amount I present at my disablement centre, only requiring yearly maintenance visits instead of socket castings and tweaks. **Improved Psychological Well-being:** The increased comfort, mobility, and functionality provided by my osseointegration positively impacts my psychological well-being and self-confidence. This has led to greater independence, social engagement, and overall quality of life. This increased confidence has allowed me to find work and become an active member of society again. My osseointegration offers a revolutionary approach to prosthetic limb attachment, addressing my limitations and challenges with traditional socket-based systems. By providing a more secure, comfortable, and functional interface between the body and the prosthetic device, my osseointegrated prosthesis empowers me to live a more active and fulfilling life.

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How did the procedure positively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
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At the point on my life when I put myself forward to have DSF done under the research project at [REDACTED], I had failed to walk for 2 years using conventional sockets. I was 21 and wanted to live my life independently and DSF was the only route I felt that could get me walking again. The research project was run by an enthusiastic team which included a Surgeon, rehab consultant, specialist nurse, physiotherapist, psychologist and if needed an occupational therapist. It was a multi disciplinary team approach. When this team approach is used, the most success occurs. When I finished rehab with my first implant I returned to work, an independent life, carried a child and lived a 'normal' life with normal mobility. I was a gym participant for 5-6 times a week and also became a qualified fitness instructor and worked in the industry. The fitness I was managing easily, would not have been possible with a socket prosthetic. I had no infections, no pains, and no issues for 9 consecutive years. I was a mum to my Son, I could carry him and see to his needs, plus join him on climbing frames and bike rides as I lived as normally as a non amputee. With a DSF I could wear normal clothes without there being an unsightly plastic socket pushing out, I would sit comfortable without a socket digging into my groin, and I could wear my leg all day everyday. I wouldn't dread having to walk a distance as I was pain free. This is how DSF should be. I could walk unlimited distance with no pain. Unheard of for an amputee. I was also a competitive cyclist and did lots of challenges with my prosthetic leg on, and again no pain or limit to the distance I could cycle. For my mental health, I didn't feel different anymore. I didn't feel at a disadvantage to anyone else. I could work full time, I could do normal activities and live a normal life which I would've had I not lost my leg. When my DSF has worked, I've not felt disabled. But when issues happen, the team needs to be available and experienced enough to deal with it.

How did the procedure negatively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
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I can honestly confirm, there has been so side effects at all, if you take up the rehabilitation and loading correctly, listen to your surgeons and keep the stoma clean, there is no negative symptoms at all, indeed, not everyone will be the same, but try and push where you can, it will help your healing, I have even after the initial six months, tried chlorinated swimming water, and in my case, this caused no reactions at all and I now swim in any pool and have never had a reaction, but I do clean the stoma after every swim to insure there are no issues. As I am so much more active and alert, it gives my a great sense of well being and this is reflected by my family, I am much more involved, and I am so proud to show people my implant and Prosthetics, they look great and that makes me feel great.

IP survey IP692_2

How did the procedure negatively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
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I would not say that there have been any negative effects from osseointegration on my life. Although I am not able to run now I did not manage to run with a socket because the pain from the socket prevented me from doing this. Initially I was not able to go swimming but I have been able to returning to swimming after my consultant agreed that the healing process of my stoma was sufficient to allow me to do so. I had to take antibiotics for a few months after my procedure to keep infection at bay but do not take anything presently. I spend a little time in my daily routine caring for my stoma and ensuring it is clean but this is minimal and has become as normal a part of my routine as cleaning my teeth. I am aware of the risk of infection and sometimes this causes me to worry a little but I have a good relationship with my consultant with whom I keep in regular contact so as to discuss any concerns I may have. Obviously, since this is a fairly new procedure there are no real indications of the longevity of osseointegration but I would rather have fewer years with a better quality of life than a lifetime of wearing a socket that imposes many limitations.

I only experience some aching when the weather is cold, but I beleive that is mainly due to the DHS and not the OI implant. Apart from that I have experienced absolutely no negative impacts in my quality of life as a result - except the financial hit I took by having to fund the surgery and prosthetic knee myself.

I can think of no negatives to this procedure apart from the totally acceptable risk of infection.

Originally the procedure was excellent but as the years passed, the aftercare deteriorated. I started having regular issues with the abutment where it would rotate more than the acceptable allowance. This meant trips to Sweden which was time consuming and sometimes, downright annoying as the repairs used to be performed at [REDACTED]. I then started having the abutment screw breaking unexpectedly, on one occasion the day before I was due to take my then 2 year old son on holiday. Another failure was 2 days after I'd secured a permanent job after being out of work for many months. I lost 19 weeks work waiting to visit Sweden for the replacement. I had a new abutment and screw in March 2023 and it has already worn even though the past 12 months have been the least active I have have been since having the implant. The loss of the holiday was most annoying but the loss of earnings certainly took their toll on me mentally as I have been suffering with bipolar depression for some time now. The depression has made me isolated and certainly had an effect on people I know. Of course, the implant is not solely to blame for my state of mind but it certainly didn't and is still not, helping..

The only issue I had was was given a blood thinner after my skin craft and end of have blood clot on my lungs and was identified and treated as it should. I do have pain around the stump but that is manageable

The only down side I have come across is not being able to going swimming with my son, but in my opinion it's worth the sacrifice

This surgery has had no negative impact on my life what so ever it has done nothing but improve and added to my quality of life

I now use at least a stick when walking outside but is a very small price to pay for the long term benefits.

The procedure and recovery/physio was grueling but I was made very aware of this before I started and the benefits outweighed the year of surgery and rehabilitation. When the bolt does break (which is inevitable given the usage) it can have a negative affect on my mindset. However, this is usually temporary whilst I am being repaired and my state of mind improves very quickly once I am fixed.

IP survey IP692_2

How did the procedure negatively affect your condition and/or your quality of life?**Please consider things such as:**

- Your physical symptoms
- Your ability to perform daily activities
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My negative effects have been few and far between. In periods of extreme cold and heat, I feel the conduction through my osseointegration. Not being able to run is probably the one thing I wish I could do, but as I get older, I wonder how much I would be running if I was able bodied. There are places I cannot go due to the risk of falling and breaking my implant. In February 2020 I did fall and snap my femur with my implant inserted. Thankfully, this was a clean break at the head of my femur, and a DHS was inserted to stabilise and strengthen my osseointegration. I have suffered from reduced bone density in parts of my body, not localised to my implant site. I have treated this with vitamin D3 and calcium supplements. I only have two speeds of walking - slow and stop! Extra consideration is needed for trips out on foot, knowing the limits of my own abilities.

It hasn't.

No negative effects.

No negative affects

the only negative thing about the procedure was the time from 1st op to 2nd op and them to walking, this took nearly a year out of my life. Its a marvelous procedure

Osseointegration surgery, while offering significant benefits for amputees, has also presented specific side effects. It's important to note that the severity and occurrence of these side effects are mild and infrequent. Pain and discomfort: I have experienced varying levels of pain and discomfort following osseointegration surgery. It seems to coincide with the changes in the seasons from cold to hot weather and vice versa Nerve Damage: During surgery, nerves near my implant site sustained damage, leading to numbness, tingling, or altered sensation in the surrounding areas. However, these sensations are thankfully limited. Bone Resorption: I have experienced a loss of bone density around my implant site and in other areas of my body since my operation. This loss in density has compromised my stability, resulting in a break of my femur and corrective surgery. Psychological Impact: Rehabilitating after such a large operation and adjusting to a new prosthetic limb was frustrating. The feeling of starting over again caused minor anxiety as I adapted to changes in my body and mobility.

How did the procedure negatively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
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- The effect on family, friends and others

The point where my pin snapped and I had big pain was the turning point. No test confirmed infection but yet I was unable to cope with the pain and ended up in A&E on numerous occasions not being able to cope. After a year of this I asked for the implant to be removed and that was when bone infection was found. There was no definitive test which could confirm the injection only the pain and suffering I was experiencing. Some of the symptoms of infection can be different from person to person. You need a experienced team to be able to handle the problems and issues that can happen with this procedure. Its not a one stop fix. Its a life long treatment which needs support when problems arise. Experiences shared and understood will help issues be overcome. But ignoring early warning signs and there being delays in seeing the correct people to step in and help, is where the program needs to be run with the patient at the centre. I have had numerous surgeries abroad in Sweden and more recently Holland due to the UK not having the skills to pick up the issues. I have experienced some of the most debilitating pain and decline in mental health when I've had no support for my issues. But prior to issues faces, DSF is by far the best treatment for amputees who cant get a comfortable socket to walk on or use. Not all patients are suitable and good well being and self care is critical. When my first implant failed I really did suffer a lot, due to the team disbanding at [REDACTED] and the need to rely on trips to Sweden being the only option to be seen and listened to. It was an extremely hard time. I was a single mum, a self employed fitness instructor and my health was deteriorating with every flare up. Support is the key and if I had this it wouldn't have been so awful. My third implant was put in 2019 in Holland by a team who were extremely experienced & the rehab protocol was essential to my success. I've had great success with this current implant but I have also experienced complications due to having such a short leg. The skin and bone interface (including the stoma) is very important to get right. I have had numerous revisions to try to correct this issue and some of which has been self funded. Its a real shame its resorted to this route for me, but living with infection and nerve pains without a route to help it, is not sustainable to anyone. I haven't used my leg in a normal way for over a year now, and I'm hoping my last revision will have sorted these issues. Its fair to say I've had the best and the worst of DSF and this is why I feel my input is so needed. I don't feel regret or bitterness for what my journey has been, but if other patients could benefit from my experiences then its a positive outcome. At my worst times my issues have stopped me working, living a normal life and also caused depression and very low mood. All fitness has been forced to stop, weight gained has occurred and that impacts the patient and the family. Not pleasant.

Did you require anymore treatment, including procedures or surgery after this procedure?



IP survey IP692_2

If yes, please provide further details.

Refashioning of the stoma after 6 months. This was a much smaller procedure and I was up walking on my prosthetic leg soon after having surgery and returned to normal life the next day.

A few physio things to do with gait, alignment of the prosthetic. Having to have the dual cone replaced every few years and general physio - apart from that nothing

Antibiotics for the occasional infection.

As mentioned, numerous breaks of the abument screw and premature wear of the abutment.

My abutment has broken on several occasions needing further surgery to replace it.

Broken femur on my implant side needed repaired. This was caused by a slip and fall causing over extension.

I need a refashioning

Over the last 8 years or so the abutment fixing in the implant has failed meaning trips to Sweden for repairs which can take time to organise so you are on crutches or wheelchair

Unfortunately, I slipped and fell in wet conditions in 2020, breaking my femur at the neck of my implant. I needed a Dynamic Hip Screw and pins to repair the damage to my implant. Thankfully, I healed and recovered well, with no lasting side effects.

With my first implant I needed a pin replacement when it snapped. Biopsies to find infections. Implant removal. Second implant I needed bone biopsy to check for infection and re-install of DSF over 3-4 operations. 3rd implant was bone biopsy and then implant install over 2 operations. I've had 3 revisions of the skin and flesh in over past 15 months. It should've been only 1 revision but the first revision caused lots of additional issues and infection. I have self funded the solution to these issues out of desperation and I will be back on my DSF leg soon. My journey proves that its not just a one operation fix. Its a ongoing journey.

Would you recommend this procedure to another patient with your condition?

Yes (16)  100%

No (-)

If yes, what might you tell them?

Its the greatest single thing that you can do to getting on with your life, indeed, life without sockets and straps is great, you can get back to doing what you want to do, after all, life is for living, not regretting.

I would say that this is a decision they must make after considering many factors because everyone's lifestyle and situation is different. I weighed up the pros and cons and decided that this procedure was one I definitely wanted to have. I have not had a single regret because osseointegration has made a remarkable difference to my life and has vastly improved the quality of my life in so many ways. There are no guarantees but life does not come with guarantees!

If you can afford it - don't hesitate. In fact I have already recommended it to some people I know

It will totally transform their lives in both comfort and mobility abilities. The prosthesis feels so much more part of your skeletal frame and you can actually feel through it unlike a traditional socket.

It has given me easy access to go in and out of my car and the ability to walk long distance and increase my quality of live and rely on my se look f most of the times

I would tell them to use sockets first, I feel like if you go straight from amputation to this you might expect it to be perfect which it's not. Without know the pain of sockets you won't appreciate the benefits of Osseo

Your ability to walk will improve drastically as will your energy levels will get so much, it will get rid of any issues with sockets and weight gain/loss and it will massively improve your quality of life

If yes, what might you tell them?

It's not an easy decision to make but if they are unable to wear a socket it is a beneficial alternative. They would have to be willing to go through what for me was a painful procedure and understand that they wouldn't have a limb for at least 6 months although I'm led to believe this is a shorter period now.. also to have it done as soon as possible after the initial amputation when their muscles are still in good shape and haven't atrophied due to a different way of walking using a socket.

It would really depend on the person and their situation but if they were the same as me... On the positives I would advise about the lack of socket/crutches use associated skin issues on the leg and hands, the speed of donning and doffing the prosthesis, the normality that comes with being back on two legs (ie not being asked or stared at), the ability to be much more independent in a world that doesn't cater well for disabled people and the longevity of the device compared to a socket that would need adjustment due to weightloss etc. There are also negatives in the fact that it can fail and does require additional surgery. The rehab is not quick and needs commitment and that you are limited in terms of exercise and weightlifting.

If you want to live an all but normal lifestyle and provided you look after your body, this procedure will afford you that ability. I visit my prosthetics centre once every two years, for maintenance and servicing. It's as close to being able bodied as I've been since my injury.

If someone has short stumps and bad scarring this procedure is worthwhile. If you have perfect stumps I don't think it's necessarily needed.

Need to research the different systems and providers available thoroughly.

The benefits far outweigh the negatives. Meaning you are going to lead a near normal life as possible

Information is power. Go into the whole process with your eyes open. Understand the risks and the benefits before committing to this surgery. Try to reach out to other osseointegrated amputees and ask questions.

I always like to promote DSF but I also like to inform of the issues that could happen as I feel transparency and honesty is the only way. Of course I would promote this procedure as it gave me an amazing life back after amputation. But the team who deliver it and their experience/expertise/ability to see you in a timely manor is all critical to the success to the patient. I would warn them of the possible issues you could face, but ultimately when it works, there is nothing that comes close to a normal life after amputation. And this goes for physically and mentally, in unmeasurable amounts of both.

If the procedure had an impact on any other areas of your life that are not covered by the questions above please tell us about them here.

Just would like to add, most amputees suffer from other issues which are directly related to the amputation, limb pain, socket discomforts, poor esteem, back and muscle issues from being out of balance etc, but having an implant allows you to be free from all of these issues, when your not in pain, you activity increases and therefore you are not being suppressed by medication etc, but you must listen to the surgeons, consider other things such as TMR, but most of all, be positive, fully engage with the journey, as life afterwards is great,

Bone scans taken prior to the procedure and also a year after having the procedure showed that the bone density of my residual limb was almost back to normal after osseointegration. After amputation the bone density of my residual limb had deteriorated quite rapidly and therefore I was worried about the risks of osteoporosis.

I've mentioned it a few times, but as one of the few patients who has had to self fund the procedure - the financial implication is huge. For the NHS, the cost of my care (excluding the cost of my emergency care) - the cost of all my operations, hospital stays, physio, prosthetics, scans/xrays, medication, counsellors etc to keep me walking runs into multiple millions of pounds, but yet the cost of this surgery is just (or was when I paid for it) £50,000. The cost saving to the NHS is phenomenal to the point where it shouldn't even be up for discussion for those patients who are suitable. The implication OI has had to my mental health, independence and social life is priceless.

The procedure has a positive impact on all aspects of my life. Confidence, walking ability, mental wellbeing and the lust for life has returned.

If the procedure had an impact on any other areas of your life that are not covered by the questions above please tell us about them here.

As mentioned, originally it was a life changer but since the original team have either retired or left [REDACTED], the aftercare has plummeted. It's like we are the forgotten few. I now consider the implant as a liability as I'm nowhere near as confident using it as I was originally. Nowadays the situation is, wait til it breaks then we'll look at it! Previously, we had two appointments per year to check everything was as it should be...unlike now.

No

N/A

The procedure had a massive positive impact on my working life. Since having osseointegration, I have been able to attend all of our sites and attend all work meetings that may have not been possible in a wheelchair. I can easily network with people too as I am at the same height and not sat in a chair. It makes me feel so less disabled in a working environment.

Being able to commit and participate more in work has meant an increase in pay which is never a bad thing.

None at all

This procedure has given me a second chance at a (almost) normal life. I cannot put a price on how it has changed my life for the better; thank you!

Your working life can be hugely impacted by this procedure. When its working well after rehabilitation finishes you are able to do fairly limitless amounts. But when you face issues it can really impact your working ability. I had first hand experience of this where I build a fitness career over years, for it to be gone in weeks once my problems started. It affects mental health tremendously when a patient isn't listened to and treated in the way of problem solving. The impact to your family and those around you who have to navigate the journey with you can be difficult too.