



# JOINT POTENTIAL 2016 -2021 EVALUATION REPORT

SCOTLAND  
VERSUS  
ARTHRITIS



Laura Johnson Consultancy



**VERSUS  
ARTHRITIS**

# INTRODUCTION

“

We are delighted to bring forward this report, highlighting the work of the Joint Potential Plus project, working in partnership with young people with arthritis and their rheumatology clinicians over the last 5 years.

Joint Potential has supported young people with arthritis across Scotland for over ten years, working hard to deliver high-quality self-management support by securing small trust awards and valued donations, but we wanted to do so much more, to plan beyond a years' funding and establish the long-term partnerships so vital to achieve meaningful change.

In 2015 we took a strategic look at the Young People and Families Service using the insight and feedback from our young people and Youth contact volunteers, incorporating their feedback on safe and supported transition within Rheumatology services. We also looked at how we could work collaboratively with clinicians and teams to achieve better outcomes for young people with arthritis. We were successfully awarded five years funding via the Impact Fund from the Health & Social Care Alliance in 2016 to support our aspirations and ultimately deliver Joint Potential Plus. This funding has transformed our work across Scotland. The impact of 5 years of sustainable funding has enabled the integration of our approach into rheumatology clinics across Scotland, opening up self-management support to young people and their families and firmly placing it on the agenda for patients from paediatric through to adult services. Joint Potential Plus, a once aspirational project has become a programme for real and lasting change. We have embedded new ways of working, and are delivering an award-winning self-management programme, with outstanding partnership collaboration across health teams with and for young people and which is integrated as part of NHS Rheumatology services.

The project is more than just self-management support for young people today, it provides a platform for young people to grow, share and learn together, ensuring their experience, and their voices are heard and can support and influence change for young people with arthritis and their families in the future.

Joint Potential Plus alongside healthcare professionals has supported young people beyond their health and care needs, supporting them with work, further education, relationships, coming to terms with diagnosis and transitioning to adult services. Not only has this been beneficial for young people and their families, but it has also had a positive impact on health professionals and health services with now established system change, developing a pathway and new ways of working in Rheumatology. None of this could have been achieved without working together and without the belief, commitment and investment of our young people, our project volunteers and staff, Rheumatologists, multi-disciplinary teams and the ALLIANCE.

”

**SCOTLAND  
VERSUS  
ARTHRITIS**

*Angela Donaldson-Bruce*

**Angela Donaldson-Bruce**  
**Scotland Versus Arthritis**  
**Director**



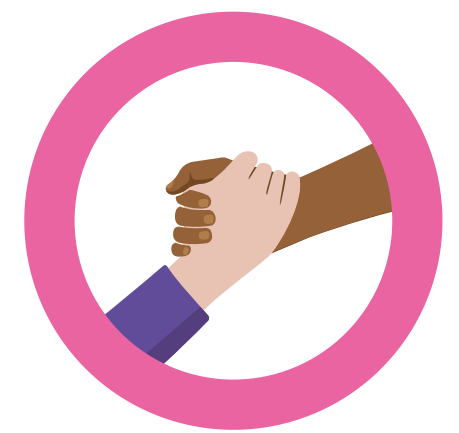
# EXECUTIVE REPORT

**Joint Potential is part of Versus Arthritis' Young People and Families Service in Scotland and supports young people aged between 16 and 25 who have arthritis. Joint Potential is a peer support and self-management programme, that delivers a programme of workshops to support young people with all aspects of their condition. It is also embedded in rheumatology services to make sure there is an integrated and holistic approach to supporting children, young people and families.**

**Joint Potential has been funded for the last five years by the Scottish Health and Social Care Alliance, which has allowed the project to develop and expand further. As this funding comes to an end, the team commissioned an independent consultant, Laura Johnson, to carry out a review of the project. The purpose of the review was to understand and demonstrate the impact of Joint Potential, particularly on the young people who have been supported, as well as to draw out lessons learned so that the project can continue to develop and improve in the future.**

## The key findings from the review were as follows:

- **Joint Potential fills a big gap in support for young people with arthritis:** arthritis is often thought of as something that affects older people, leaving a big gap in support for younger people, particularly around self-management, the non-medical side of living with arthritis, and peer support. Clinicians involved in the work within the rheumatology clinics explained that Joint Potential also provides holistic all-round support that is missing within the system.
- **Peer support is a crucial element of what makes Joint Potential work so well: with arthritis affecting a relatively small number of young people,** it can be hard for young people to meet others in a similar position to them. Young people interviewed talked about how this can leave them feeling very isolated, particularly as their lives often change quite dramatically at the time of their diagnosis, and how much having someone to talk to helped them. The Joint Potential team make sure that peer support not only happens at the workshops and weekends, but that it continues outside of Joint Potential too.
- **Young people report feeling less isolated, more confident and more able to manage their condition and its impact on their lives as a result of Joint Potential:** young people supported through Joint Potential report feeling less isolated, and more confident, especially in taking control of and managing their condition and its impact on their everyday lives. One of the other main benefits of Joint Potential is that it helps bring a sense of normality – young people are given the space to be young people, with the comfort of knowing that people around them understand their arthritis.
- **There is likely to be a positive impact on the wider family:** although the young people themselves are the main focus for Joint Potential, it was felt that there was a positive impact for the wider family. If a young person is in a better place with their condition, and are more able to self-manage, then it is likely to have a positive impact on their family. In addition, the work in clinics helps to take some stress away for families and makes sure parents are feeling comfortable when a young person goes into an appointment on their own for the first time.
- **Volunteering for Joint Potential is a rewarding experience:** volunteers are crucial to the delivery of the project, and report gaining a lot from the experience. As well as gaining skills, interviewees talked about a sense of satisfaction from helping others who are in a similar position they were in. Volunteering also offers a progression through the project and older volunteers serve as role models for the younger participants. It also means that those who have transitioned through the project still have a good peer support network, as the volunteers can continue to support each other, as well as continuing to learn from the young people who are being supported.
- **The clinic work has enhanced Joint Potential's impact and clinicians highly value working with the team:** the clinic work has been massively instrumental in growing the project, with staff reporting that it had led to an increased referral rate, a greater level of trust among young people and their parents and carers, and improved content as the team have been able to work with medical professionals on it. The close relationship the Joint Potential team have with the young people also means that they can work closely with the clinicians to flag any issues or concerns. Clinicians were very positive about their experience and really valued the contribution of the team, seeing them as an essential part of the service and improving the offer for young people.



- **The willingness and ability to adapt the project and respond to needs has been crucial to success:** much time has been spent over the last five years responding to the needs of young people and adapting the workshops and weekends. This commitment to constantly reviewing best practice and what's working and not working was felt to be one of the reasons why Joint Potential had engaged young people so well.
- **A foundation in youth work and youth involvement has been critical:** staff felt that having a firm foundation in youth work has been fundamental in making Joint Potential so successful. This approach makes Joint Potential's work person centred and directed by young people, making sure that young people are involved in shaping what the project is doing. The voice of young people has been a very prominent and key feature of Joint Potential, and fundamental to the way the team operates. In particular, the strong volunteer base has been an extremely useful asset to help develop activities. This has also meant that the voice of young people with arthritis has become more respected and listened to within Versus Arthritis as a whole.
- **Support for young people aged 25+ is an area for development in the future:** currently Joint Potential is aimed at young people aged 16-25, but young people say that they feel support drops off at this age. This was also noted by Versus Arthritis stakeholders, who said that the charity needs to work out what the offer should look like and whether they need to support young people aged 25 and above to transition to adult services and support, or whether something else is needed for this 'middle' group.



- **Balancing resources between those with high level needs and those with mild or moderate needs has been a challenge:** since the clinic work has started, the team has been dealing with a greater number of young people with more diverse needs and more support needs. This has been challenge given the level of intensity of the programme, and the space and time that is given to each of the young people involved, making it difficult to balance the range of needs.
- **There's a desire to scale up the clinic work but it is resource intensive to set up:** stakeholders spoke about the desire to have the clinic programme rolled out across more clinics in Scotland, and to get clinicians more involved in the workshops and events, with a much stronger partnership between the project and the clinicians. However it was noted that the clinic work has been very resource intensive to set up and it will take a significant amount of time and resource to roll the programme out across Scotland, because of the need to gain buy-in from health professionals, navigating the different ways of working among the different health boards, as well as the resources that are required to cover the geography with only one staff member.

- **An opportunity to continue what has worked well during the Covid-19 pandemic:** the team have had to adapt delivery during the pandemic, introducing more digital elements that have worked well with the young people. This will not be able to replace the face-to-face delivery, but some stakeholders said that it would make sense to plan a more comprehensive offer that included the digital elements and more creative approaches that have worked well during this time. In addition, the digital delivery has highlighted how isolated some young people are, and how lockdown has affected their mental health, making this a need going forwards.
- **Learning should be used to shape any 'scaling up' of the service across the UK:** Joint Potential was seen by all stakeholders to be extremely successful in Scotland and to have demonstrated a social model of support for young people, based on a youth work foundation. Stakeholders commented that there is now an opportunity for Versus Arthritis to build on this success and consider how this model could be applied to other parts of the UK.



**It is clear from these findings that overall, Joint Potential is a very successful project. It has developed and grown significantly over the last few years, and made a huge difference to the lives of the young people supported.**

**In order to strengthen this further, it is recommended that:**

- the Joint Potential team continues to deliver the excellent programme of work, incorporating elements of digital delivery that have worked well during the Covid-19 pandemic to complement the existing offer;
- Versus Arthritis considers and shapes its offer for young people aged 25 and above, working the Joint Potential team to ensure their learning and expertise is fed in;
- further funding is sought to provide the necessary resources to scale up and roll out the clinic work across Scotland;
- additional expertise within Versus Arthritis (such as the health information, professionals engagement and influencing teams) is drawn upon to support the scaling up of this work in Scotland;
- consideration is given to how and whether this model of working can be scaled up across the UK, using the key learning points in this report about what has made it work so well;
- the monitoring and evaluation processes for Joint Potential are reviewed, to ensure there is more robust evidence collected on a regular basis.

**Joint Potential, part of the Young People and Families Service for Scotland, is a programme of events for young people with arthritis and related conditions, aged 16-25 years old. The aim is to ensure that young people with arthritis are more resilient, less dependent and more confident and empowered:**

- young people have the skills and techniques to enable them to confidently manage their condition
- young people have the confidence to take control of their lives and manage transitions in their lives
- young people feel less isolated by their condition and have an established network of peer support

## Activities

The project delivers residential weekends and one day events that are open for anyone with any form of arthritis or related joint condition, living anywhere in Scotland. The events are offered for free to young people, and the project covers travel expenses, accommodation and food.

Residential weekends start on a Friday evening and finish after lunch on the Sunday. There are 12 participants, supported by volunteer Youth Contacts who are all young people with arthritis. During a weekend, common themes are explored through a range of group discussions and activities. There is also a fun activity on the Saturday afternoon, such as Mocktail Masterclasses, laser tag, go-karting and day trips. There is also free time to use the hotel facilities and chill out. Five residential weekends are held each year.

The programme of one day workshops focuses on key issues such as sleep management, pain management, physical activity, and sex and fertility. Three workshops per year are delivered as part of the project.

The Joint Potential project has also worked to become integrated into health services, working directly with clinicians within rheumatology clinics as part of a multi-disciplinary team. This involved supporting young people and their families while at clinics (e.g. sitting with them in the waiting room, preparing them for the appointment, talking to parents about what will happen at the appointment etc) and working with the clinicians and other members of the MDT to ensure that the young person's wider holistic needs are understood and addressed.

Activities are mainly delivered by volunteers, who are young people who have at least one year's experience of the project. The Young People and Families Manager, Klaire, has oversight of all the activities and leads on the clinic work, while the YPF Senior Coordinator and Artistic Lead, Jay, is responsible for the workshops and residential weekends. Joint Potential is just one part of the youth offer in Scotland and both staff deliver over a variety of other youth projects alongside Joint Potential. These two dedicated members of staff are supported by staff across Versus Arthritis, including colleagues in services, IT, HR, business support and digital support.

## YOUTH ENGAGEMENT NUMBERS

YEAR	NUMBER OF YP	NUMBER OF EVENTS	AVERAGE NO. OF ATTENDEES
2016	60	6	10
2017	85	7	12
2018	73	7	10
2019	66	7	9

The impact of the pandemic meant we had to adapt our service and the support we provide our young people to be responsive to their needs. We have recorded our figures over that period to reflect the vast increase in 1-2-1 support provided to young people in addition to our virtual and face to face events.

YEAR	NUMBER OF EXISTING YP	NUMBER OF NEW YP	STAFF INTERACTIONS WITH YP
2020-21	159	256	4394

# 1. INTRODUCTION

Joint Potential is part of Versus Arthritis' Young People and Families Service in Scotland and supports young people aged between 16 and 25 who have arthritis. Joint Potential is a peer support and self-management programme, that delivers a programme of workshops to support young people with all aspects of their condition. It is also embedded in rheumatology services to make sure there is an integrated and holistic approach to supporting children, young people and families.

Joint Potential has been funded for the last five years by the Scottish Health and Social Care Alliance, which has allowed the project to develop and expand further. As this funding comes to an end, the team commissioned an independent consultant, Laura Johnson, to carry out a review of the project.

## The review

The purpose of the review was to understand and demonstrate the impact of Joint potential, particularly on the young people who have been supported, as well as to draw out lessons learned so that the project can continue to develop and improve in the future. The following activities were undertaken as part of the review:

- Document review of all the relevant background documents, analysed data and reports available on the project
- Interviews (5) with the project team and other Versus Arthritis staff
- Interviews with young people (5) in order to generate case studies
- Online survey of young people supported (10 responses) which was co-designed with colleagues at Versus Arthritis, who also administered the survey and analysed the data
- Telephone interviews with clinicians from the rheumatology clinics (3)

## This report includes:

- Further information on Joint Potential and its delivery to date
- Key findings from the review, written up under key themes
- Conclusions and recommendations for the future

---

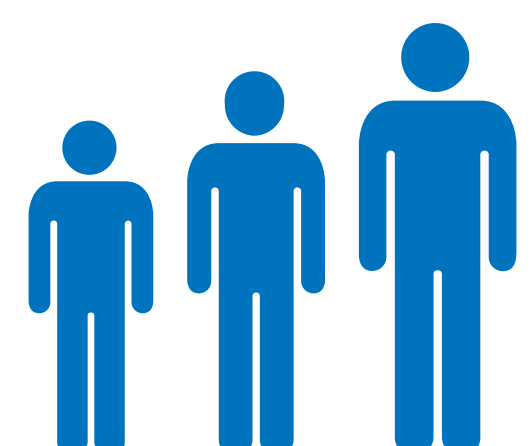
## 2. JOINT POTENTIAL



Around 12,000 children in the UK (1 in 1,000) under the age of 16 have juvenile idiopathic arthritis (JIA), and children with JIA have significantly lower physical well-being and psychosocial health (mental, emotional and social wellbeing) compared to those without. At least one-third of children with JIA go on to have an ongoing active condition in adulthood. Arthritis can impact on all aspects of a young person's life, including otherwise routine day-to-day activities, family and social life activities as well as education. The pain, lack of mobility and fatigue associated with the condition, restricts every aspect of their lives. Many young people will miss large amounts of school because of their condition and going out with friends can be difficult. This results in feelings of isolation, depression and over dependence on parents.

Versus Arthritis' ambition is that 'every young person has the support they need, when they need it, to live well with their arthritis', and has been delivering its Young People and Families (YPF) service for over 25 years. The service began helping young people with arthritis in Northern Ireland in February 1995, rolling out to Scotland around 10 years ago.

**SCOTLAND**  
**VERSUS**  
**ARTHRITIS**





## Co-creation with young people

A core principle of Joint Potential is to develop the content and approach to the workshops and residentials in collaboration with young people. Drawing on the expertise of the volunteers who are young people with arthritis themselves, with experience of being supported by Joint Potential, and through ongoing feedback from the young people themselves, the content and approach to the workshops and residentials is continually evolving to ensure it best meets their needs.

“

**‘We have quite a lot of time with our volunteers as well as our young people to look at what topics that they want to explore, and what are the sort of issues that they have coming up, and a lot of that will come through being away or spending time speaking to them as well... there's always common themes that are coming up that you're recognising, especially recently, mental health being a big one, and with young people in lockdown, and being able to then realise that there's a theme here that we need to address. We work with them to understand so what are your priorities in this? What things would you like to see? And working with them and our volunteer team to make sure that we're able to address those and be responsive to those needs.’ (Versus Arthritis staff)**

”

---

## 3. FINDINGS

This section provides the key findings from the review, presented against key themes that emerged across the review.

### Joint Potential fills a big gap in support for young people with arthritis

It was clear from all stakeholders involved in the review that Joint Potential fills a huge gap in support for children and young people who are diagnosed with arthritis. Arthritis is often thought of as something that affects older people, and younger people have different support needs to older people. The project was set up to fill that gap of support for the 16 to 25 year olds with arthritis and related conditions, focusing in particular on self-management and the non-medical side of living with arthritis, and facilitating peer support.

**‘It was just that recognition of actually, that arthritis isn't still seen as an older person's disease. And so making sure that there was actually dedicated support and a dedicated service for those under 25 with arthritis related conditions... there was just absolutely no support, and so it basically just stemmed from what young people were telling us.’ (Versus Arthritis staff)**

”

“

**‘I think there's been a massive unmet need there for years. And we still see that in the young people that we're meeting that have literally never met another young person with a condition similar to them, that don't have support, that maybe are accessing the NHS but are actually not engaging at appointments or are struggling to keep up with medication regimes, and all that sort of stuff. So there's a massive need there for support for young people who are isolated. (Versus Arthritis staff)**

It also provides that holistic all-round support that is missing within the system. One clinician explained that even within their MDT, which included a range of specialisms and support, there was a gap before they started working with Joint Potential.

**‘I know that medical support is just one element of what young people need – psychological support, family support, occupational support, physio etc – and all of these things, we as clinicians are not good at providing this support. They could be on the right medication but it could be the other issues that are affecting their progress. This is where the focus on the MDT has come from. So however clever the clinician is, if he is working solo, he won't be able to deliver the right support for these people. We have been lucky to have a clinical psychologist and their support has made a big difference. But still that wasn't enough because you need someone at the end of the phone, someone to link with education and employers, someone to support self-management and talk about common issues – this was the lacking part and this is where Joint Potential fitted in.’ (clinician)**

## Peer support is a crucial element of what makes Joint Potential work so well

The peer support was highlighted as one of the most important aspects of Joint Potential. Arthritis is often associated with older people and affects a relatively small number of young people, meaning it can be hard for young people to meet others in a similar position to them. Young people interviewed talked about how this can leave them feeling very isolated, particularly as their lives often change quite dramatically at the time of their diagnosis.



“

**'I suppose the main benefit, and the main impact, is that access to peer support, and young people meeting each other... that's massive. It's not just linking people up but actually, young people that know the journey that you've been on, can totally understand about pain, fatigue, medication... they've then got somebody that can understand their situation, but also that they're able to work with each other and support each other through the really tough times.'** (Versus Arthritis staff)

One member of staff explained that the team make sure that peer support not only happens at the workshops and weekends, but that it continues outside of Joint Potential too.

**'the friendships continue and a lot of them are in touch. They've got like a Facebook page and stuff that people can talk on and, you know, connect and stuff. It's nice to see that they have been hanging out [outside of the sessions]. They wouldn't say hello in a clinic waiting room, that's just teenagers. So if we're able to link them up, that's brilliant.'** (Versus Arthritis staff)

”

This was echoed by younger people who talked about the difference peer support had made to them.

“

**'I think the peer support is definitely the biggest one for me – because you get that not just from the participants but the volunteers and the staff, because they have a lot of knowledge and experience as well. Just to be in one place where there are lots of people going through the same thing as you and they can really empathise.'** (young person)

”



## Young people report feeling less isolated, more confident and more able to manage their condition and its impact on their lives as a result of Joint Potential

The peer support, including the support from volunteers as well as other participants, has helped young people supported through Joint Potential to feel less isolated. Staff reported that young people leave the events feeling like they've made best friends, especially where they have attended residential weekends and had the chance to really bond over their shared experience. This was echoed by the young people themselves.

“

**'At that time, I think I just wanted people to relate to because I was the only person I knew in my age group that had it. So there were parts of my life that people didn't understand. But I ended up getting a lot out of it and I felt more positive when I came home, and I was picking up tips from other people. It helped me to gain confidence, and it helped me to understand my condition. It gave me a support network. I felt quite isolated before, and now my best friend has arthritis and lives 5 mins away.'** (young person)

Staff and young people also talked about the increased confidence young people experience as a result of Joint Potential. This included self-confidence and assertiveness, including confidence in attending medical appointments and speaking to professionals, and taking control of and managing their condition and its impact on their everyday lives.

**'It's really allowing them to take ownership of who they are and where they want to go in their life, and giving them that control back. And I guess that goes hand in hand with giving them the confidence to manage their condition as well... being able to actually feel in control of their bodies and realise that they still have an element of control, and giving them that power back to make life choices for themselves, is really empowering.'** (Versus Arthritis staff)



One of the other main benefits of Joint Potential is that it helps bring a sense of normality – young people are given the space to be young people, with the comfort of knowing that people around them understand their arthritis.

**'At the activity weekend they do accessible activities, and it pushes you a bit to do something you wouldn't normally do otherwise. And it's nice to do it with people who are not storming ahead. It gives you a bit more of a sense of normality and inclusion.'** (young person)



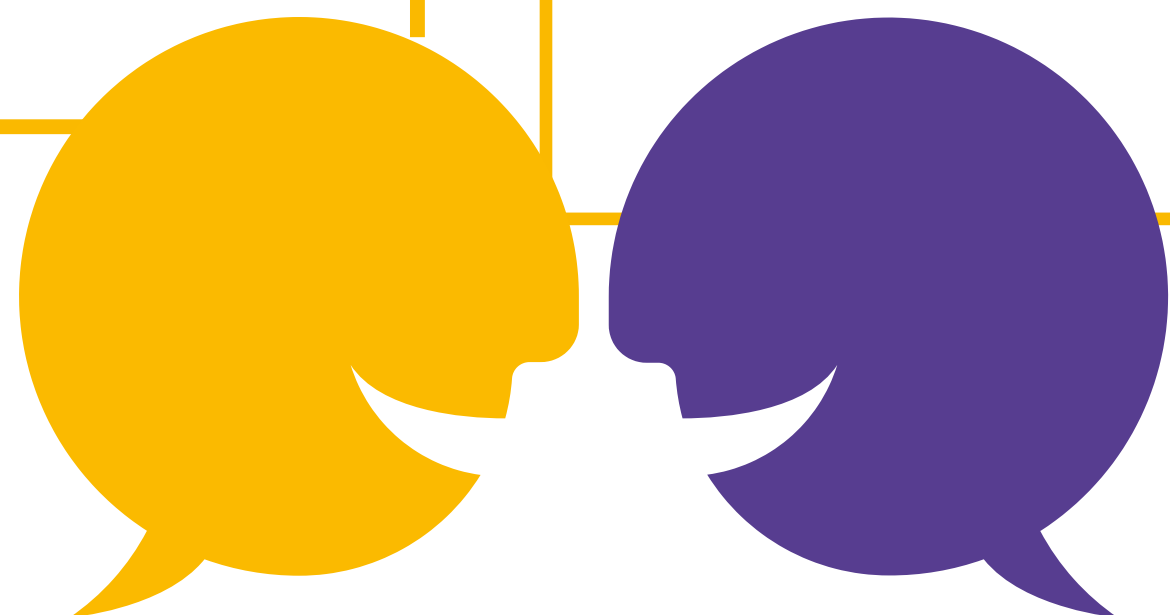
**'the medical aspect of living with arthritis can be really overwhelming. And what we want to do and what I suppose one of the bigger impacts that we have is that young people can come to a weekend or come to a workshop and actually not necessarily have to talk about their arthritis all the time... I think one of the biggest impacts that is being able to bring them together and just give them a place where they can just be themselves and that they don't have to worry that if they're too sore, or they're not going to manage, because we try as a staff and volunteer team, we try to really make them as accessible as they can be... we build the entire weekend so that it takes the pressure off the young person so they can come and just be a young person for the weekend. And hopefully, while they're there enjoy themselves and learn something new about how to live well with their condition.'** (Versus Arthritis staff)



Ultimately all of this leads to an improved ability to self-manage, helping young people to live well with their condition and make their own choices to live the lives they want to live.

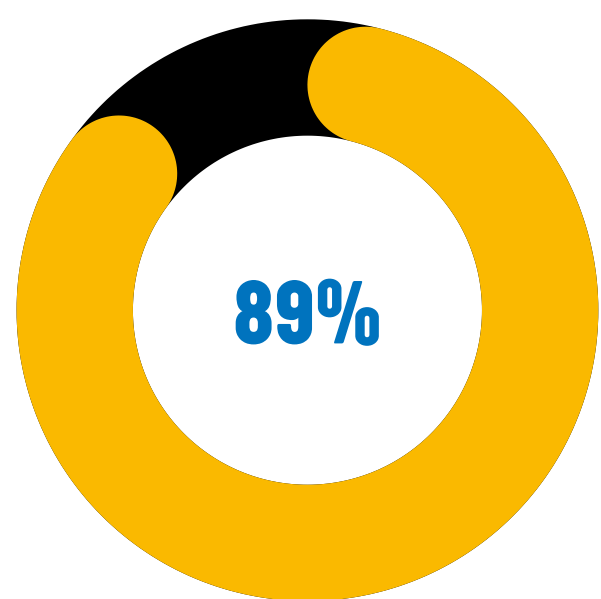
**'I suppose the biggest difference that we would see is where young folk are actually confident to take those steps into their career path, or through education or wherever they're going, and to be able to manage and live well with their condition. So it's no longer you know, defining who they are. They're actually learning how that is part of them.'** (Versus Arthritis staff)

**'I just think the staff and the volunteers are phenomenal – they definitely deserve a lot more recognition because they have helped me through the darkest times in my life so far.'** (young person)

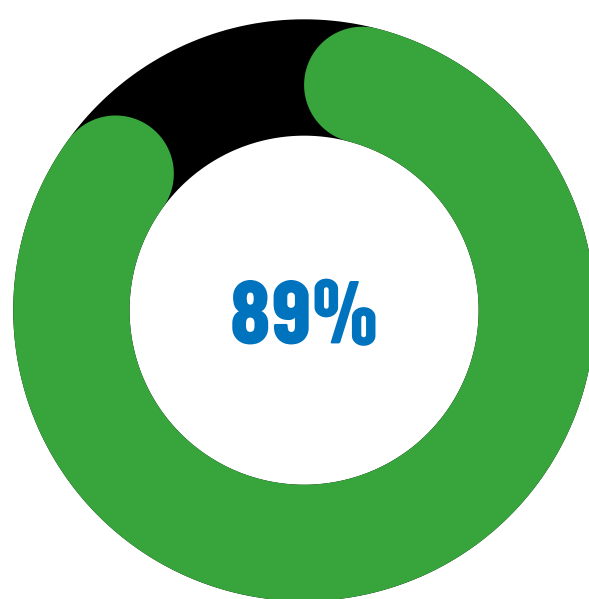


These findings were backed up by the survey of young people, in which all respondents said the service had had a huge (89%) or big (10%) impact on their lives. All respondents rated their overall experience of Joint Potential as 'excellent' and said that they would recommend the service to others. The survey provided a number of statements and asked respondents to say how much they agreed with them. All respondents agreed with all of the statements, and the table below shows the percentage of respondents who strongly agreed.

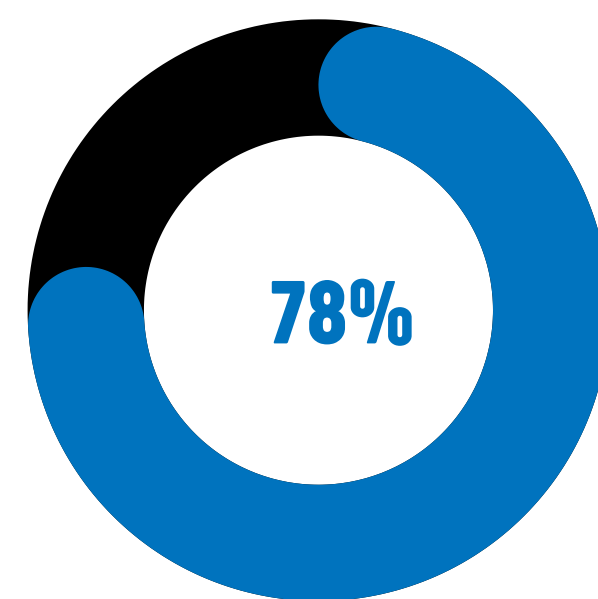
Joint Potential has helped me to meet other young people in a similar position to me.



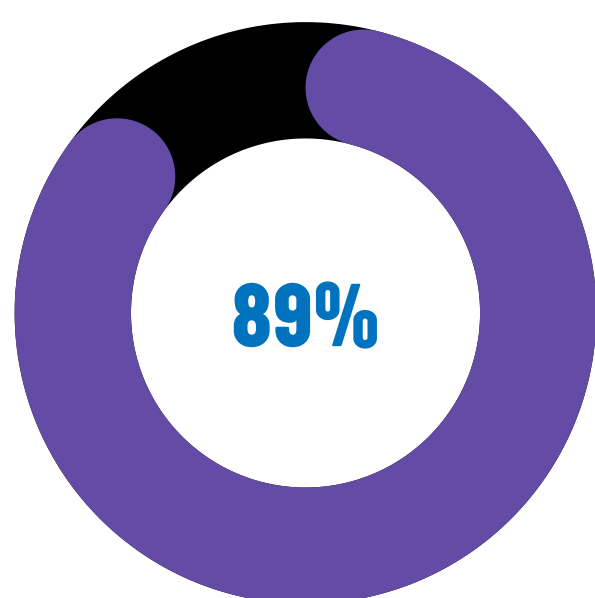
Joint Potential has made me feel less isolated and alone



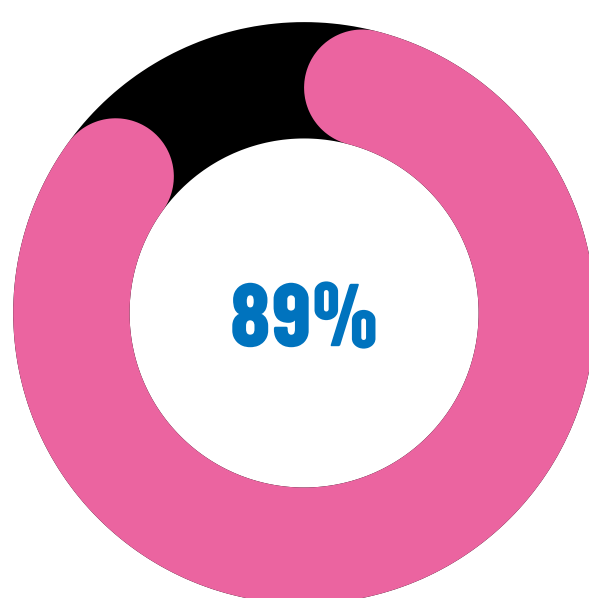
Joint Potential has made me feel more positive about my condition



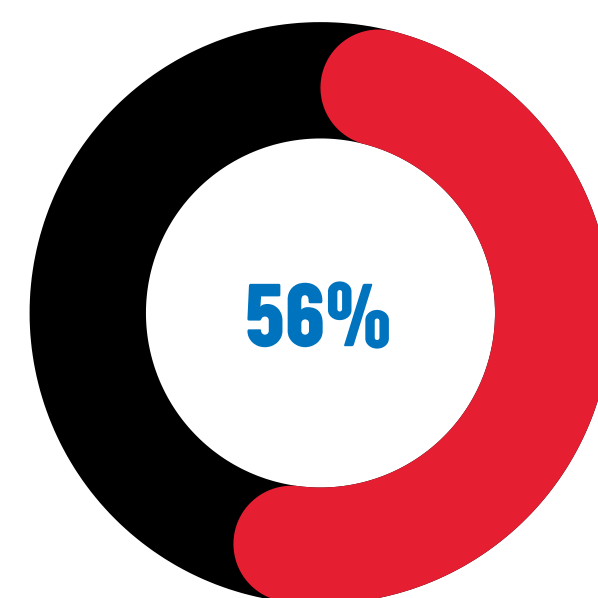
I feel more able to manage my condition



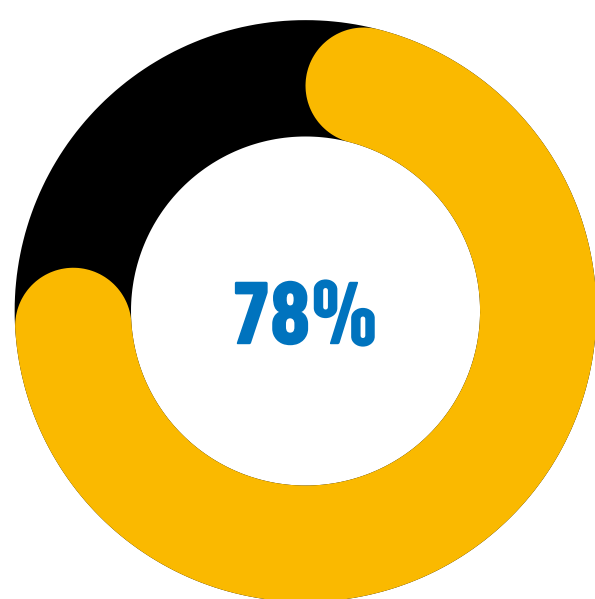
I now feel more confident about expressing how my condition affects me



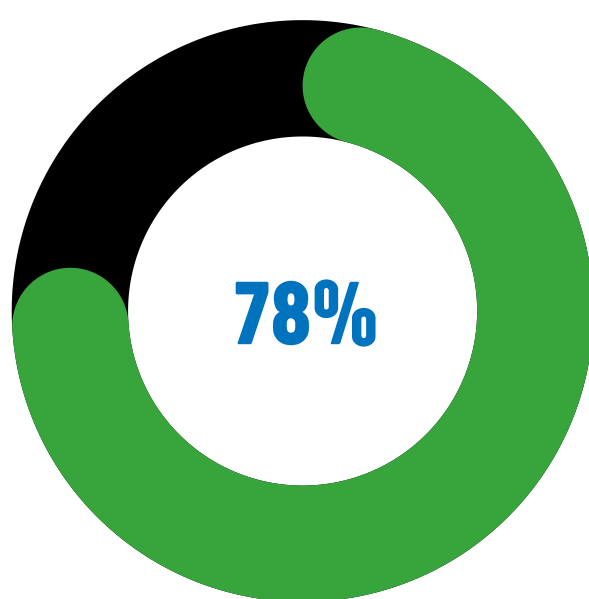
I feel more confident voicing my opinions and needs with professionals



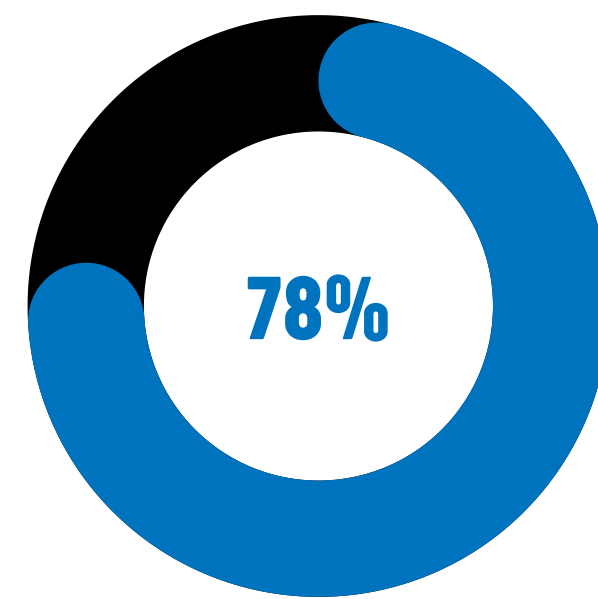
I have high hopes for the future because of Joint Potential



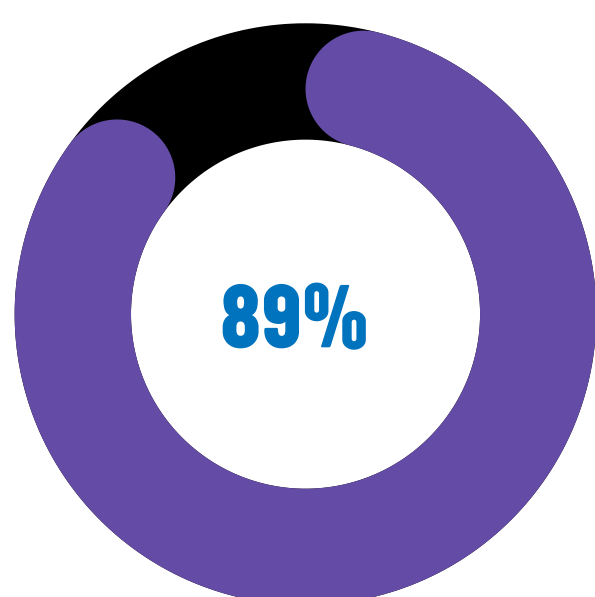
My mental health / mood has improved as a result of Joint Potential



I have more confidence in being myself because of Joint Potential



I have made positive changes to my life as a result of Joint Potential



Below are some real life case studies of young people who have been supported through Joint Potential. The case studies give a more in-depth view of how Joint Potential has made a difference to their lives.

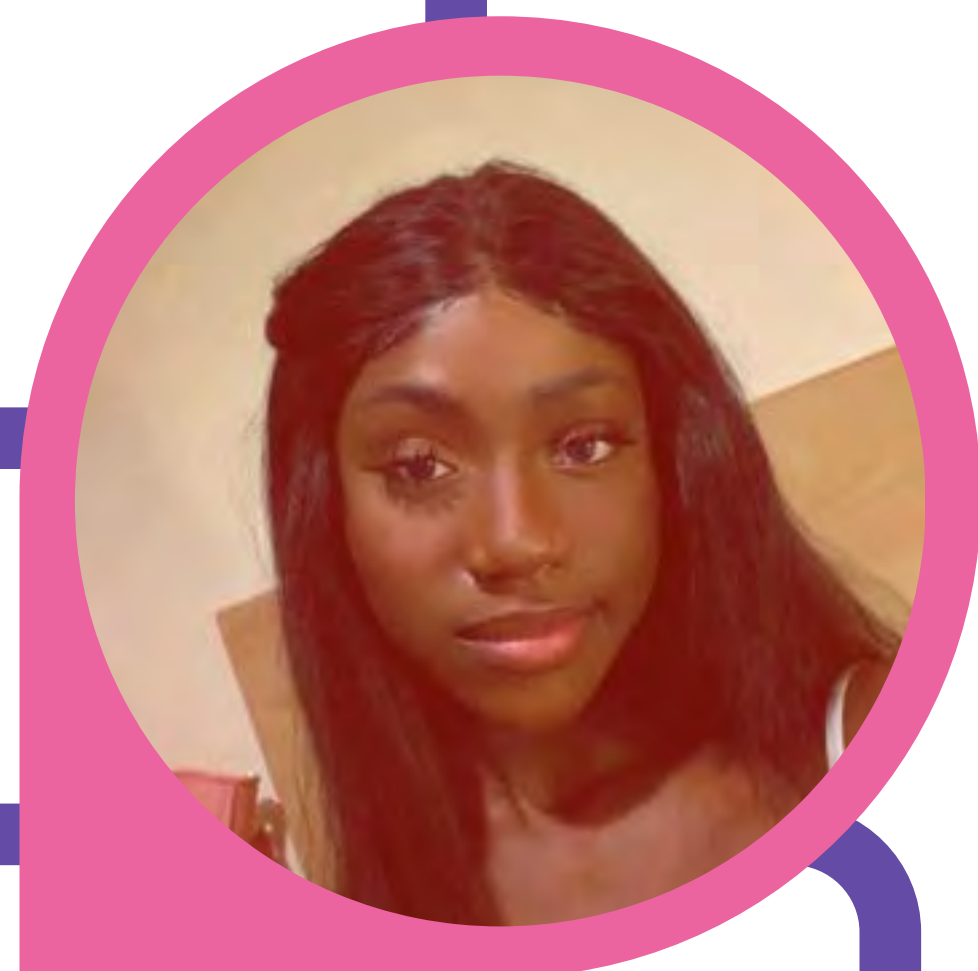
### Kiana's story

'I was 13 when I was diagnosed with arthritis and we weren't told about any support groups or anything. It wasn't until I was transferred to adult services that I met Klaire [Young People and Families Manager, Scotland], and she explained to me about what the team offer.

I signed up for the spring weekend away and met more of the volunteers and young people with arthritis. Since then, I've gone to lots more weekend trips and I feel like I have such a big community now, whereas I felt alone before. No one else knew what arthritis was and what it was like to go through it, whereas I know lots of people now going through the same thing.

I definitely feel I have a lot more freedom and a lot more confidence. I understand the patterns we end up in and I know where to go to find information. Klaire has also helped me personally in my rheumatology appointments. I was having some issues explaining and being understood by my rheumatologist, but Klaire spoke to him and asked him to hear me out and listen to me. I am extremely grateful that she has stepped in as someone who has been able to open the conversation. She was also there each time in the waiting room before my appointments which really helped... as a listening ear and a familiar face.

One of the other big things is that when I met Klaire, I was just a few months away from starting college and I didn't have much faith I would complete my course. But it gave me the confidence and showed me where there was support and what I was entitled to. I wouldn't have completed the course if I hadn't have had the support.'



### Christine's story

'I'm 18 and I have JIA. I first heard about [Joint Potential] in hospital. I didn't know many other people with arthritis. I went on one of the residential weekends. I went up to Aberdeen and stayed in a hotel, and there were three other girls who joined the same day. That was about a year and a half ago.

I've been to other workshops since then and there was a family thing last week. It's quite good and everyone is really nice. It's good at the residentials because we have chance to relax and chat to other people, people who have been through similar experiences, like the older girls.

[The main benefit for me has been] getting advice and how to get help with your condition. I was in my last year at school and they helped me to talk to the teachers when I was changing schools. That would have been harder [without Joint Potential] because it's hard for the teachers to understand. It's been good for making new friends too.

I would like to be a volunteer in the future – I want to help people who are younger than me.'

## Megan's story

'So I was diagnosed with arthritis when I had just turned 18. I spent the first couple of months after my diagnosis feeling a bit lost – all of my friends had left me because we were of the age where we could drink, and I couldn't do that. It's hard for people to empathise if you haven't had experience. My clinician recommended Joint Potential. I went to my first weekend a couple of months after I was diagnosed. It was the activity weekend. I had to get the train all by myself, which was really out of my comfort zone, but when you're desperate for that support you'll do anything.

I don't think I've missed a residential weekend. I love the feeling of being surrounded by amazing people and the support you get. You get the late night chats and the dinner chats, and all the info you wouldn't get from your rheumatologist. I found it really useful.

I think the peer support is definitely the biggest [benefit] for me – because you get that not just from the participants but the volunteers and the staff, because they have a lot of knowledge and experience as well. Just to be in one place where there are lots of people going through the same thing as you and they can really empathise.

[My family and I] had a massive conversation a year after we'd been, and a lot of my family members have commented on my confidence and my ability to move on from things. Before, if something happened to me, I would be really dramatic and it would be really hard to move on from things because I didn't know how. My mum has mentioned a few times that she feels relieved that I have someone to turn to talk about things.

I honestly don't know [what would have happened without Joint Potential]. I don't know where I would be because at that time of my life, I was in a really dark place and they lifted me out of that. I have met some of the most amazing people and got the most amazing support, and I don't know what I would have done without that. I do struggle to get through some days. I'll definitely stick with it for a long time to come. It's not that I can't do it without them but it's good to be with them. The peer support is absolutely phenomenal.

I just think the staff and the volunteers are phenomenal – they definitely deserve a lot more recognition because they have helped me through the darkest times in my life so far.'



## Alex's story

'I was diagnosed with rheumatoid arthritis and through the different departments, I had an occupational therapist and she suggested I go to one of these events. That was roughly 5 years ago. I was 25 so I was just at the upper age limit. They let me go because I had just been diagnosed.

I've been a participant in almost all of them now and about 2 years after I became a volunteer. It's good for both meeting people in your kind of age range, and just being able to talk to people who completely understand where you're coming from. From the actual workshops, you get information and suggestions on things, and about managing your condition on a day to day basis.

I definitely would be struggling more [without Joint Potential]. I wouldn't have been a happy bunny because I would have felt alone. I did lose some friends because some people didn't understand that I couldn't go out all the time anymore, so I would have felt a bit lost. My life changed dramatically when I was diagnosed. I wouldn't have known what support to ask for with work too – I had to change my job when I was diagnosed, and I was struggling with being seated at my desk. The DWP give a grant to your workplace and I wouldn't have known that if [it wasn't for 'Joint Potential']. It's good to have a mix of day workshops and weekend workshops. It's really good that it's funded so people don't have to worry about how to get there and getting food when they get there, which makes it easier for some people, especially if they are travelling from Aberdeen or somewhere quite far.'



## Shaunie's story

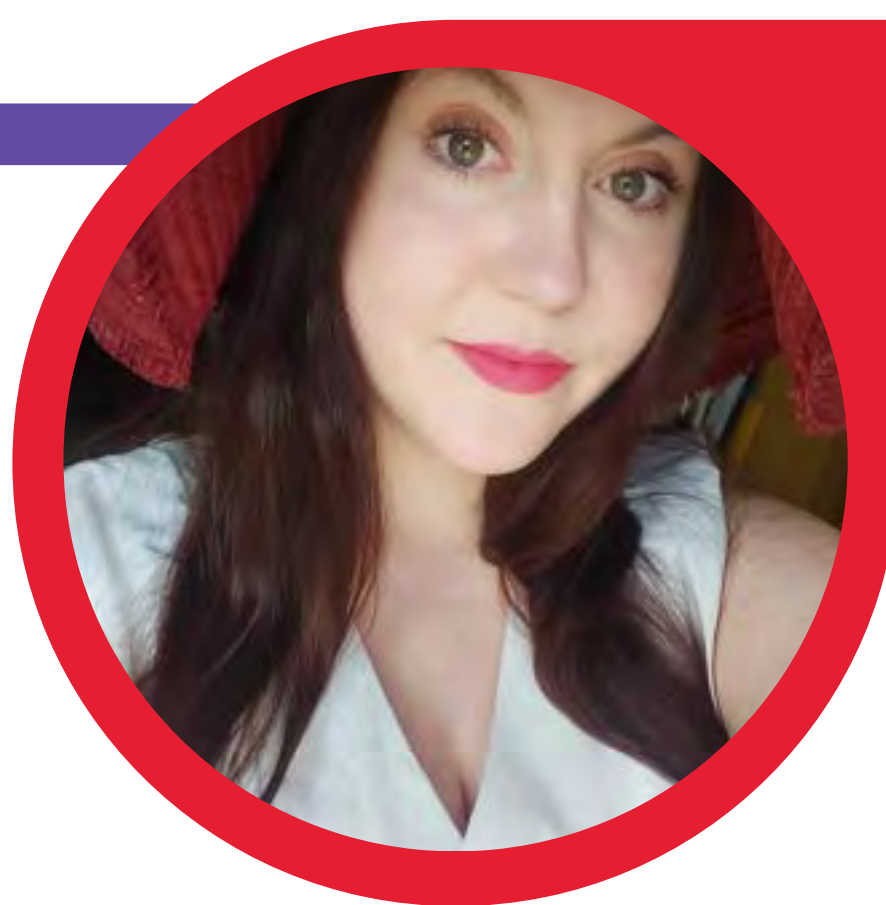
'I was diagnosed with rheumatoid arthritis in 2016 and I was in the adults clinic, so the people in the waiting room weren't really people I would connect with. I moved to the young adults clinic and I met Klaire there. It wasn't until I was in a really dark place that I decided to go, and I really loved it. And now I'm a volunteer too. It was a lifeline for me.

At that time, I think I just wanted people to relate to because I was the only person I knew in my age group that had it. So there were parts of my life that people didn't understand. But I ended up getting a lot out of it and I felt more positive when I came home, and I was picking up tips from other people. It helped to gain confidence, and it helped me to understand my condition. It gave me a support network – I felt quite isolated before, and now my best friend has arthritis and lives 5 mins away.

The [workshop] that has been most useful for me is the sex and fertility one – it was really good and really helpful, because my clinician wasn't very open about that. I now have a 5 month old. Travelling takes a lot out of you, so the option of residential weekends really does help. Sometimes it's nice not to have to worry about the dishes and things like that. The thing I really enjoy about is hearing other people's experiences and not feeling alone. It's nice taking inspiration from people you wouldn't have otherwise met, and having that open conversation. Sometimes you don't want to bog friends and family down.

Joint Potential is brilliant. It has really helped me to accept arthritis. I was really depressed when I first started going, but I've learnt to embrace it and recognise that it doesn't have to affect all parts of my life. It's helped me to advocate for myself with employment for example. It's made me more happy. It was affecting my relationship with my fiancé, but now that I've made that support network, I can turn to them. My partner knows there are some things I'd rather talk to them about than him. I lost quite a lot of my friends when I got arthritis and I only had him before.

I think that my disability maybe would have got worse [without Joint Potential] just because of the way I was feeling mentally. That was affecting my physical health. Joint Potential has made me realise that there are things I can achieve and do that I never thought was possible. I'm now at college and I'm a mum, and I don't think that would have happened without Joint Potential. I'm thankful to Joint Potential.'



## There is likely to be a positive impact on the wider family

Although the young people themselves are the main focus for Joint Potential, it was felt that there was a positive impact for the wider family of the young people supported through the project. If a young person is in a better place with their condition, and are able to self-manage better and do regular day-to-day activities, then it is likely to have a positive impact on their family.

“ ‘we went to an arts workshop thing and there was a show at the end, and my parents went. They got to meet some of the people [that work for Joint Potential]. They got an understanding of what things are like for us too. It's good for them that I have other people to talk to other than them.’ (young person)

“ ‘My mum has mentioned a few times that she feels relieved that I have someone to turn to talk about things.’ (young person)

In addition, the work in clinics helps to take some stress away for families, supporting the young person to talk about what they are worried about and making sure parents are feeling comfortable when a young person goes into an appointment on their own for the first time.

'part of my job in clinic is to almost distract the parents when the young person goes into an appointment by themselves, because it's gonna be a massive, massive step... all of a sudden, we're going through this process where we're trying to get the young person really independent and confident about talking about their own medical issues... a parent can sometimes find that really, really stressful. And so some of the work that I do is basically to chat through with the parent what appointment is going to look like, making sure that we build the parents confidence in their young person.' (Versus Arthritis staff)



## Volunteering for Joint Potential is a rewarding experience

Staff and volunteers reported that the volunteers, who are crucial to the delivery of the project, gain a lot from the experience. As well as gaining skills from the training that is provided and their experience of delivering sessions at the workshops and residential weekends, interviewees talked about a sense of satisfaction from helping others who are in a similar position they were in.



'I guess a sense of satisfaction, helping other people as well like you got support when you were a participant, and knowing you've maybe made a difference to somebody. (volunteer)

'I would say the confidence is a big one, I think the skills and the training that is given, has been fantastic and is really transferable not just for this, but for other things as well... there's a diverse range of topics that we've covered over the years that really upskill you not just for your volunteering role, but are really transferable for sort of university or workplaces as well. But I would say that there's the sense of being a really close knit team, that when you go away on weekends... we always have a brilliant time and everybody always take something away.' (Versus Arthritis staff)

In addition, the volunteering experience offers a progression through the project, with some volunteers having been with Joint Potential right from the very beginning in 2010. These older volunteers serve as role models for the younger participants who look up to them and aspire to be like them and volunteer in the future for Joint Potential.

'we've got some of the younger people coming through from the younger project as well that are now transitioning over and looking to become volunteers... those young people sort of look up to them as role models and say, when I grow up, I want to be doing what you're doing... it's just something that I think gives all of us the fire to keep wanting to go ahead with it and keep sticking with it. Everybody's so passionate about what it is that they do, which is fantastic. Our volunteer team are just amazing.' (Versus Arthritis staff)

The volunteering experience with Joint Potential means that those who have transitioned through the project still have a good peer support network, as the volunteers can continue to support each other, as well as continuing to learn from the young people who are being supported.

'we do have a volunteer group that meet regularly... they have extended friendship groups as well and chat to each other. Whatever we do, there's no point in a bunch of adults telling young people about self-management or better ways to live, but actually coming from a young person who's been there and done that is massive... And what we then have is young people learning from volunteers and our volunteers also learning from the young people, which is brilliant.' (Versus Arthritis staff)



## The clinic work has enhanced Joint Potential's impact and clinicians highly value working with the team

The clinic work has been massively instrumental in growing the project, with staff reporting that it had led to an increased referral rate, a greater level of trust among young people and their parents and carers, and improved content as the team have been able to work with medical professionals on it.



'when I started, it was a big leap of faith to send your young person or to be a young person to commit to going away with a bunch of people you don't know. So that has made a massive difference there. And we've been able to enrich what we've been offering by being able to work more closely with medical professionals in terms of our content... So all of the clinic work has really complimented and fed into what we've been able to do for the workshops and weekends...I don't think we would be where we were with the residentials. and stuff, if it wasn't for the development of the clinic work alongside.' (Versus Arthritis staff)





It's a mutual relationship – they are meeting YP who they might not otherwise meet, so they are getting more people at their workshops. It raises the profile of the charity which is did not have before.' (clinician)



Staff reported that the unique relationship that the Joint Potential team have with the young people also means that the young people are much more likely to tell them something than they would be their clinic team. This means that the Joint Potential team can work closely with the clinicians to flag any issues or concerns.

**'we'll find out on weekends that actually they've decided to take themselves off all their medication, which can be quite dangerous if you don't come down off medication gradually and things. So being able to work with them and give them the support to then feed that back into their team, allows them to get a better outcome for their health.'** (Versus Arthritis staff)

Staff also felt that it was a good opportunity to show health professionals the value of working with a third sector organisation and bring a new way of working to the clinics. There was a recognition that the NHS is stretched and health professionals do not always have a lot of time to give to patients, and the Joint Potential team are better placed to talk to the young people about their concerns.



**'it is sometimes just actually the fact that they're speaking to a doctor and doctors are held in high regard and I think sometimes they're just a bit terrified that they're maybe not going to understand or something just feels like such a little thing that actually, are you going to talk to your consultant about that? Potentially not... I think a lot of the time, the impact that we have for health professionals is that if we are able to help that young person in the family, explain their issues, and explain what's going on and actually explain what they need help with, then that goes a really massive way... So what we do, is we try to have that conversation of right, this is a clinic today, this is who you're going to see, have you got questions that you want to know, have there been any massive things that really impacted you that you really want to talk about? And it's about making sure that the young person is that kind of frame of mind to be as open and honest with their clinician as possible.'** (Versus Arthritis staff)



Clinicians who have been working with the team were also very positive about their experience and really valued their contribution. It was clear that they saw them as an essential part of the service – improving the offer for young people and also helping them to focus on the clinical aspects of their role.

**'I feel I'm leaving patients in safe hands – these people are clearly very experienced. They know what the role is, they know how to handle things, they know what appropriate workshops each individual can benefit from, they know what information to point them to, they give them a pack of useful websites they know will help them. I used to do all of this but now it's all done on my behalf by them. It's a two way process – she refers to me and I refer to her. I think it's an enormous support... Service users find this to be extremely helpful. They feel well supported, not just medically, but all other aspects... the whole department are well aware of how enormous the support we're getting from Joint Potential is on this aspect. It paid off and people are well aware of how useful this addition to the service has been. We hope to continue to work closely with Joint Potential and have this support.'** (clinician)

“

‘Self-management is an enormous issue for us – we are looking to get people to help themselves as much as they can, for financial reasons and for themselves. It’s a win win situation. We have link workers in the third sector but they are not always as tuned in as the Joint Potential workers – the things they are talking about are on the nail, and they are very specific to arthritic conditions. [Klaire is] such a key part of the team. Joint Potential provides just an amazing service to us... We would be absolutely stuck [without it] and we would have no alternative... more of it [across Scotland] would be good because it’s such a valuable service.’  
(clinician)

## The willingness and ability to adapt the project and respond to needs has been crucial to success

Staff reported that over the last five years, they had spent a lot of time adapting the workshops and weekends, in order to be responsive and to stay relevant. The team regularly review how things have gone, what feedback they’ve had from the young people and make changes accordingly. A key change over the last few years has also been to ensure that there's plenty of space for young people to talk and to work through some of their issues for themselves.

‘We’re definitely not a come and we’ll tell you how to fix it. It’s very much give the young people the tools and help support them to get there themselves because everybody’s different. So it does look very different than it did maybe five years ago.’ (Versus Arthritis staff)

‘I think has been the key thing is to keep what we’re doing relevant and be able to keep changing. If something’s not worked, we’re quite good at saying, okay, that hasn’t been successful. Why is that, and how can we address that? And that’s something that we will do regularly, just to make sure that everything’s going as smoothly as possible, and that young people are getting what they need.’ (Versus Arthritis staff)

”

This constant development was felt by staff to be one of the reasons why Joint Potential had engaged young people so well. While the programme of events may look similar year on year, the content and feeling of the events has changed (and continues to change) depending on what is thought to work best at that point in time and what the young people need. So rather than having a strict timetable, the team are led by the outcomes they want to achieve in that workshop or weekend.

“

‘it’s not a programme that we will run year on year without changing... new things come out all the time, in terms of youth work, and about how we deliver and what that looks like, but also to work with the young people to recognise what it is they need... it’s flexible enough that actually the outcome and the impact will be the same, but how we deliver is very different depending on who we’ve got and who’s doing it.’ (Versus Arthritis staff)

”



“

‘so a lot of the time is working with volunteers and the young people to continually evolve and develop our programmes so that it’s not a fixed offer. And historically, it had been a series of workshops that we would run as they were each year. And actually, we realised that we needed to be much more responsive to our young people and to their needs as they evolved. And as a result, our workshops have continued to evolve, and still be relevant to them. And so we’re still approaching the same sort of things and big topics, but actually how we’re approaching it and, and how we’re exploring that together might change as well as the priorities that the young people have sort of set for themselves. So a lot of it is all co created with them.’ (Versus Arthritis staff)

”

## A foundation in youth work and youth involvement has been critical

One of the key principles about Joint Potential is that it has been developed from a youth work foundation. Staff felt that having that firm foundation in youth work had been fundamental in what has made Joint Potential so successful. This approach makes Joint Potential's work person centred and directed by young people, making sure that young people are involved in shaping what the project is doing.

As such, the voice of young people has been a very prominent and key feature of Joint Potential, and fundamental to the way the team operates. In particular, the strong volunteer base has been an extremely useful asset to help develop activities.

“

**'They [the volunteers] are the young people help us understand how we want to develop, where we need to change, where we should have new ideas, their feedback and insights are invaluable to us. And we wouldn't have Joint Potential if it wasn't for them. And we wouldn't have moved into clinic and be doing the one day workshops, because these are asks that they've come back to us with.'** (Versus Arthritis staff)

The success of the project, and the confidence of the young people involved, has also meant that the voice of young people with arthritis has become more respected and listened to within Versus Arthritis as a whole. In the last couple of years, Versus Arthritis has prioritised the needs of children and young people with arthritis in its strategy, at least in part because of the success of the project and the active involvement of the young people.



**'the Scottish group of young people are incredibly confident. They're very clear about challenging us. And I don't know whether that's a joint potential programme, or those individuals themselves, I'd like to think it is both, but they're not they're not afraid of saying what they need or afraid to say what they want. So I think that is the impact of what this programme has done for them.'** (Versus Arthritis staff)

”

## Support for young people aged 25+ is an area for development in the future

An area for future development that came up among a number of interviewees was the need to clarify what support should look like for young people aged over 25. Currently Joint Potential is aimed at young people aged 16-25, but young people say that they feel support drops off at this age and it would be helpful to have more support available.

“

**'The only thing I would say is that there is a group that is missing – technically I shouldn't be a participant because I'm over 25, and support just stops at that age group. I wish they had a 25-35 age group – particularly for people who are first diagnosed at that age.'** (young person)



”



“

‘a lot of our young people stick around for a really long time, which is brilliant, but when they age out of a project, we don’t necessarily have somewhere for them to go within Versus Arthritis. So not having a programme that looks at self-management that’s appropriate for a 25 year old... we’re quite a high intervention... but that doesn’t necessarily translate well into adult services, and that’s a massive challenge... We want to be able to keep them with Versus Arthritis, but adult services aren’t necessarily set up like that... so how do we make sure the young people know what to expect once they age out. And that’s why I think we get a lot of requests to be volunteers, so that young people don’t have to stop coming along.’ (Versus Arthritis staff)

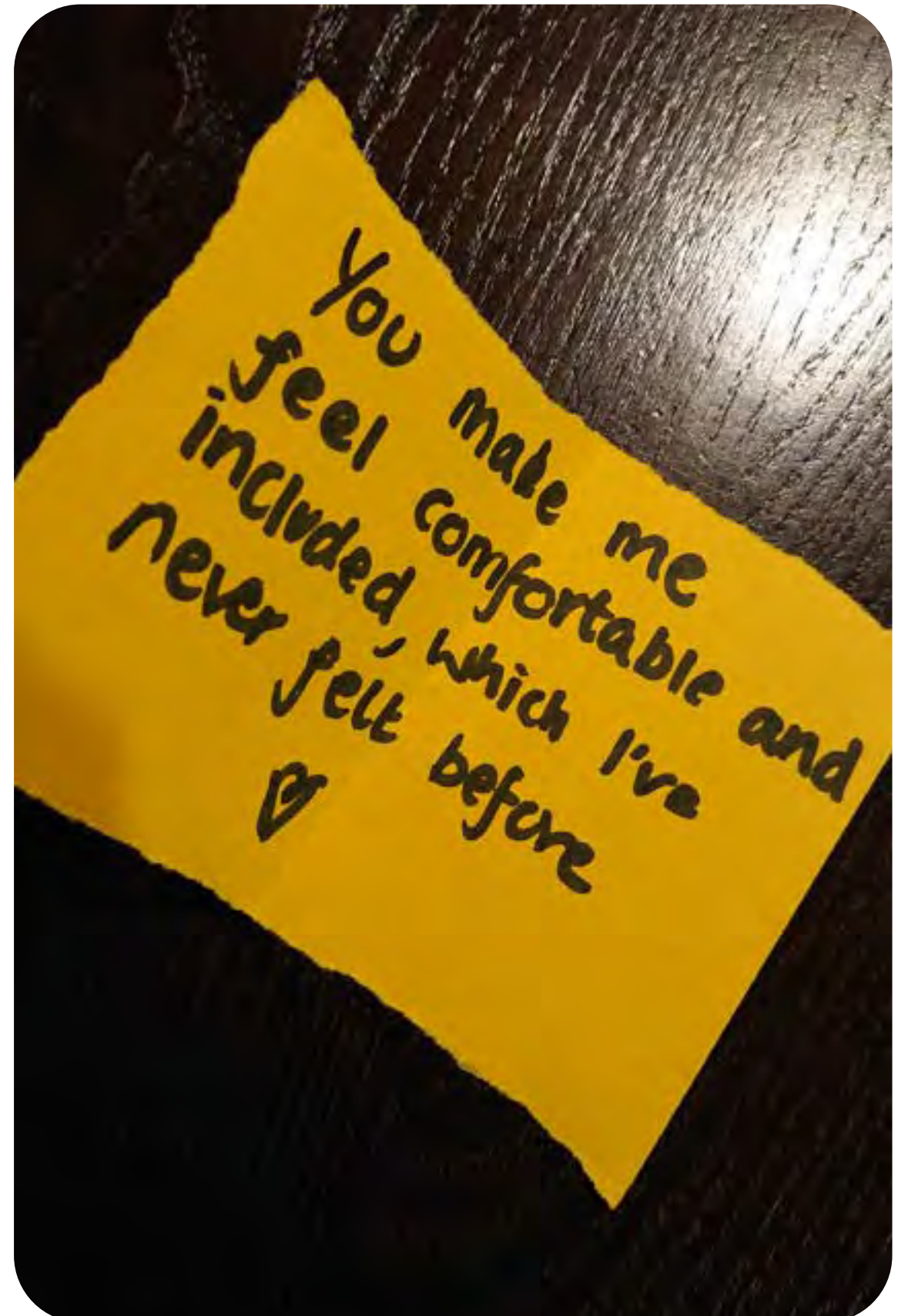
This was noted by Versus Arthritis stakeholders, who said that the charity needs to work out what the offer should look like and whether they need to support young people aged 25 and above to transition to adult services and support, or whether something else is needed for this ‘middle’ group.

‘we haven’t bottomed out the best way to give support beyond 25. So we don’t make good transitions yet into our other services, which, we call them adult services, we’ve set up these almost artificial silos of age, because that is often driven by funders..., but actually a young person that’s 23, might well want to be doing something that we deliver in our adult services, and there’s no problem with that. It’s just that we haven’t really facilitated that transition well within our own services.’ (Versus Arthritis staff)

One young person mentioned that actually one of the volunteers had set up – separate to Joint Potential – a meeting for people aged 25 to 35 to fill the gap. Clearly the group doesn’t have the financial backing of Joint Potential but offers an informal way for those who have aged out of the project to meet and offer support to each other.

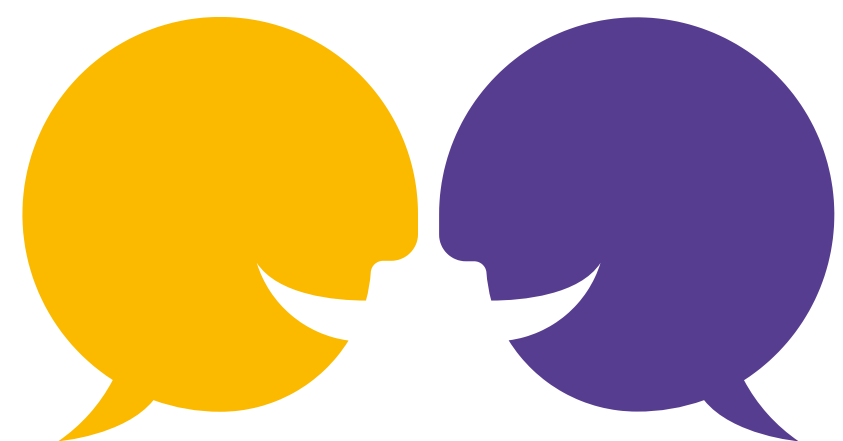
‘One of the girls runs a 25 to 35 meeting. It’s not run by Joint Potential – we get ourselves there and buy our own coffees and stuff, but we have set it up because we could do with something for the older people. It’s 2 hours every other month. It’s not directly related, but if I hadn’t have been there, I wouldn’t have come across that. Some of the other volunteers go and some of the other participants are old enough now too. (young person)

”



## Balancing resources between those with high level needs and those with mild or moderate needs has been a challenge

One of the challenges, particularly since the clinic work has started, has been dealing with a greater number of young people with a higher level of need. Historically the project had worked with young people with a similar level of need and similar condition, but as the work has progressed, there have been more young people with more diverse needs and more support needs. This has been challenge given the level of intensity of the programme, and the space and time that is given to each of the young people involved, making it difficult to balance the range of needs.





“

'I think one of the challenges of the clinics being successful was an increase of young people with more support needs... We want as many young people that will keep the weekend or the workshop beneficial. We never want to have too many on people where that loses that personal connection. But I think one of the biggest challenges that we've had is, young people with more support needs coming along, and actually, potentially not being quite ready for that... if they've got quite big support needs, then it takes more stuff, it takes more volunteers, and we want to make sure that every young person is having the best time they can, and also getting something and that the weekend is impacting them on a really positive way. And I think that's been one of the biggest challenges is how we manage the numbers of young people and the support of young people, and I suppose skills and ability of staff and volunteers to manage that. (Versus Arthritis staff)

”

## There's a desire to scale up the clinic work but it is resource intensive to set up

Stakeholders spoke about the desire to have the clinic programme rolled out across more clinics in Scotland, so that all young people under the age of 25 would feel supported within their rheumatology clinic and that there was a clear pathway from all clinics into the workshops and events. There was also a desire to get clinicians more involved in the workshops and events, with a much stronger partnership between the project and the clinicians.



“

'that would be my hope, that there's a really clear programme for adolescent rheumatology that we are then part of in Scotland. And to have a really, really clear pathway into the workshops and events. And what I'd love to do is actually get some of the clinicians involved. So some have already been involved in some of our events, but I'd really love to have a much stronger partnership and relationship with not just paediatric, but also adult rheumatology services so that there's input there from clinicians.' (Versus Arthritis staff)

However it was noted that the clinic work has been very resource intensive to set up and it will take a significant amount of time and resource to roll the programme out across Scotland.

'the clinic work has been difficult because of the amount of time that it's taken for us to get into clinics. And that can be tricky, because actually, it can take a really, really long time. So in terms of sort of staff time, it takes a lot to set all of that up..' (Versus Arthritis staff)

'I think that, you know, my hope of reaching more rheumatologist and reaching more young people is going to take some specific money behind it... and I think it probably needs a bit more input from different teams within Versus Arthritis, but also buy in from the NHS. And all of that needs resourcing in one way or another.' (Versus Arthritis staff)

”

It has taken a number of years to get into the clinics they have done, so this has been one of the most challenging areas of the work to date. Much of this is the need to gain buy-in from health professionals, but also navigating the different ways of working among the different health boards, as well as the resources that are required to cover the geography with only one staff member.



**'The biggest challenge for me was always the credibility with healthcare professionals... we have had to spend at least seven years working towards that. And so that was always a big challenge.'** (Versus Arthritis staff)

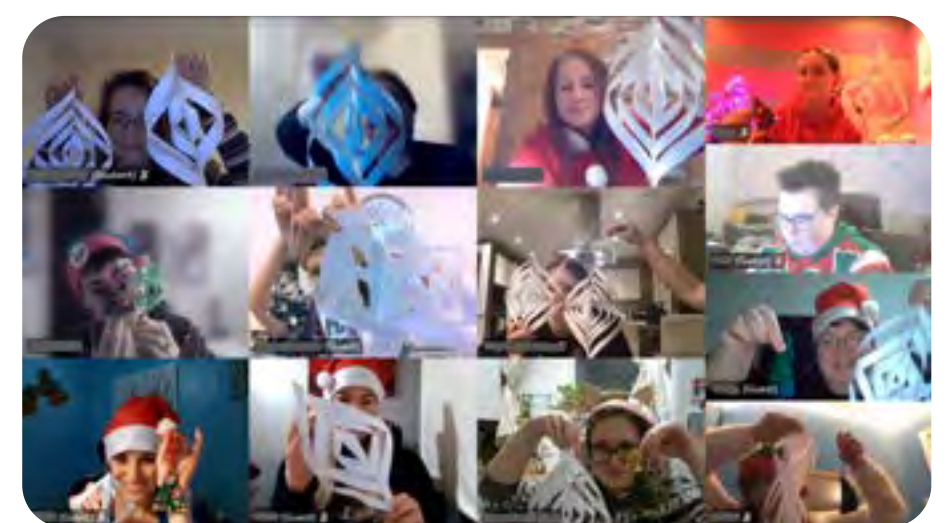
**'when we open five rheumatology clinics in Scotland, I think internally, people don't realise that they can be hundreds of miles apart... we only had one person that was able to do that so this became a really vast programme of work. What we learned was how differently each Health Board functioned, in its decisions, in its structures, in how it wanted to operate.'** (Versus Arthritis staff)

## An opportunity to continue what has worked well during the Covid-19 pandemic

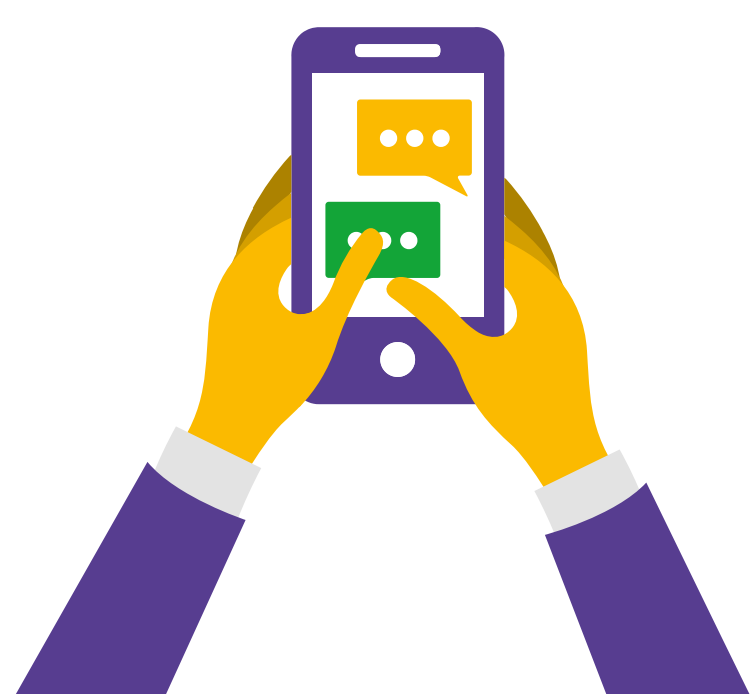
During the Covid-19 pandemic, the team have had to adapt delivery given that face-to-face contact was not possible. This included introducing more digital elements that have worked well with the young people. Obviously there is a desire to get the face-to-face delivery fully up and running again, but some stakeholders said that it would make sense to plan a more comprehensive offer that included the digital elements and more creative approaches that have worked well during this time. In addition, the digital delivery has highlighted how isolated some young people are, and how lockdown has affected their mental health, making this a need going forwards.



**'the past lockdown has given us time to take a step back and reflect on what we were offering before and the sort of changes that we've made to move to digital and stuff is really highlighted the isolation that some of the young people are experiencing, and even more so now, so there's a fair bit of work to do. There's been quite a lot of support needs arrived... and I think confidence as well is another one that's taken a big knock with our young people... I think that we need to bring our young people back to a position that they might have been in previously. And we've also been doing quite a lot more creative projects with the younger people as well, which has been really interesting, so we've been doing podcasts and stop motion projects. So there's lots of techniques and stuff that we've been looking at that are a bit different that we wouldn't maybe have done before, but have given our young people a new skill set that they can take forward. So we'd like to continue to develop and sort of innovate in those spaces as well. But definitely get them back face to face, because that's something that everybody's missing massively.'** (Versus Arthritis staff)



**'I've been going for nearly 2.5 years, and before covid, the programme was quite repetitive, but during covid they have had to adapt and overcome the whole technology and everything, so they have totally moved on. They have done a podcast and done an animation, and they are really growing. It's amazing to see and grow a bit. I've seen a lot of new faces. We had our first face to face event the other day and it's nice to see so many new faces.'** (young person)



“

'what works well is we do bring people together from across all parts of Scotland but it is really challenging sometimes because of geography. And therefore, they've had to really shift that through lockdown, and completely turn how they work and support young people on its head. And they've done a great job actually... what that's done is it's ramped up the one to one support that young people have, and how they've managed their condition, their emotional well-being through this period. So I think that's been a real pressure on joint potential in how these volunteers keep communication going. They heavily use social media, that's really important as a mechanism for them and how they keep in touch. So yes, I think I think it's worked well, because we've had to move into a different space. But what works well is they're very able to flex and adapt, and we have quite a creative team. who do quite a lot of creative stuff with youngsters, which is quite engaging.' (Versus Arthritis staff)



”

## Learning should be used to shape any 'scaling up' of the service across the UK

Joint Potential was seen by all stakeholders to be extremely successful in Scotland and to have demonstrated a social model of support for young people, based on a youth work foundation. Stakeholders commented that there is now an opportunity for Versus Arthritis to build on this success and consider how this model could be applied to other parts of the UK.

“

'the charity needs to move into that that social model of care, because that's fundamentally what we do... we've got to learn what that youth work social model means for young people, both for our opportunities to seek external funding, but also for us to learn that that is a valuable way of working. And that is actually the way that the third sector should work in partnership with the clinical setting. So it's about sharing that learning with clinicians who we may want to set up with in Wales or Northern Ireland or wherever.' (Versus Arthritis staff)

”

## 4. CONCLUSIONS AND RECOMMENDATIONS

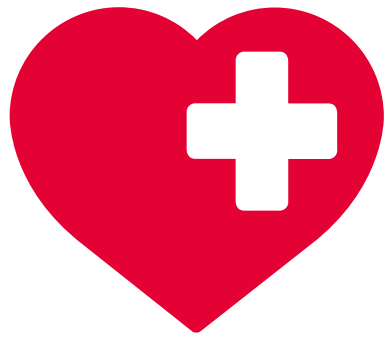
It is clear from this review that overall, Joint Potential is a very successful project. It has developed and grown significantly over the last few years, and made a huge difference to the lives of the young people supported. In particular, facilitating peer support and helping young people to make connections is one of the main benefits, especially considering that young people often struggle to meet other young people with arthritis. This, together with the information and support provided through the workshops, and the chance to try new activities and have the space to be young people, has led to increased confidence, resilience and an ability to live well with their condition.

Much of this success is down to the foundation of youth work on which the project is built, as well as the project's commitment and ability to continue to evolve and develop the offer, and deliver content that is tailored to the needs of young people. Young people and the volunteers who have come through the service are integral to developing the delivery and the team are hugely responsive to their feedback. This ensures that the content and approach suits the young people and volunteers, and achieves the best impact they can.

Although the number of people supported each year may look small when compared with other services and support, it must be remembered that this is an intensive level of support and as such, has a very big impact on the young people supported. In addition, there are only two members of paid staff, supported by a committed and engaged volunteer base that is a real asset to the project.



The clinic work is also highly valued. It has enhanced the service and support that the young people receive, and complements what the clinicians and other members of the MDT can provide. It has also helped Joint Potential to reach an even greater number of young people, and increased their level of trust in the project, as well as giving Versus Arthritis more credibility among health professionals.



The clinic work is, however, resource intensive. It has taken several years to get into the clinics and establish effective ways of working, as gaining buy-in and navigating different ways of working has taken time. There is a strong desire to roll out this model across Scotland but additional resources and greater input from other parts of Versus Arthritis are likely to be needed to make this happen in practice.

There is a need to clarify the offer for young people over 25. Feedback from the young people themselves shows that they feel the support drops off at this point, as Joint Potential is aimed at young people aged 16-25 and adult services are not geared up to support them in the same way. Versus Arthritis needs to work out its offer to this group of young people, whether that's a bespoke offer or a clearer transition into adult services and support.

The team have coped well with the challenges that the Covid-19 pandemic has brought, and have developed creative approaches to digital delivery. While there is no substitute for the face-to-face support, the digital forms of delivery have worked well and complement the existing offer well. In addition, they have helped to reach young people in more remote locations who were previously very isolated. As such, there is an opportunity to continue elements of digital delivery that have worked well during the Covid-19 pandemic to provide a comprehensive and rounded offer.



## Recommendations

**As a result of the findings, it is recommended that:**

- **The Joint Potential team continues to deliver the excellent programme of work, incorporating elements of digital delivery that have worked well during the Covid-19 pandemic to complement the existing offer;**
- **Versus Arthritis considers and shapes its offer for young people aged 25 and above, working the Joint Potential team to ensure their learning and expertise is fed in;**
- **Further funding is sought to provide the necessary resources to scale up and roll out the clinic work across Scotland;**
- **Additional expertise within Versus Arthritis (such as the health information, professionals engagement and influencing teams) is drawn upon to support the scaling up of this work in Scotland;**
- **Consideration is given to how and whether this model of working can be scaled up across the UK, using the key learning points in this report about what has made it work so well;**
- **The monitoring and evaluation processes for Joint Potential are reviewed, to ensure there is more robust evidence collected on a regular basis.**





# APPENDIX: LIST OF INTERVIEWEES FOR THE REVIEW

Klaire Connor, Young People and Families Manager, Scotland, Versus Arthritis

Jay O'Reilly, YPF Senior Coordinator & Artistic Lead, Versus Arthritis

Angela Donaldson-Bruce, Nation Director – Scotland, Versus Arthritis

Zoe Chivers, Director of Services, Versus Arthritis

Caron Jenkins, Senior Operations and Development Manager – Scotland, Versus Arthritis

Dr Hazem Youssef, Consultant Rheumatologist, Aberdeen Royal Infirmary

Dr Linda Gibson, Clinical Psychologist, NHS Grampian

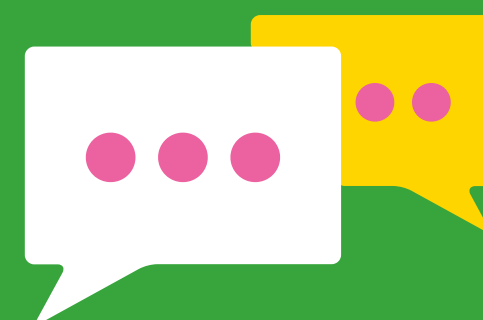
Dr Jo Walsh, Consultant Paediatric Rheumatologist, NHS Greater Glasgow and Clyde

Shaunie Smith, young person supported by Joint Potential

Megan Riggins , young person supported by Joint Potential

Alex Collins, young person supported by Joint Potential

Christine Manneh, young person supported by Joint Potential



**A special thank you to all of those involved in the creation of this report, the young people and volunteers who have been part of the project and to our funders, The Health and Social Care Alliance Scotland, without whom, none of this would have been possible.**

**SCOTLAND  
VERSUS  
ARTHRITIS**



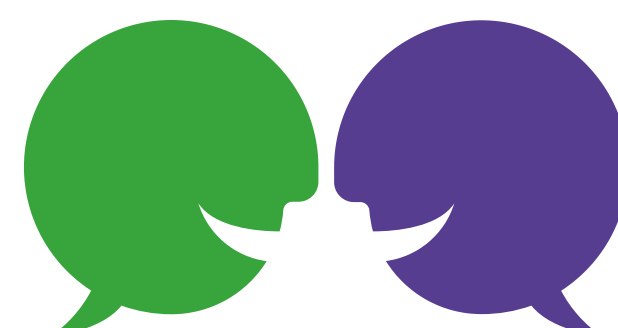
# OUR REACH ACROSS SCOTLAND

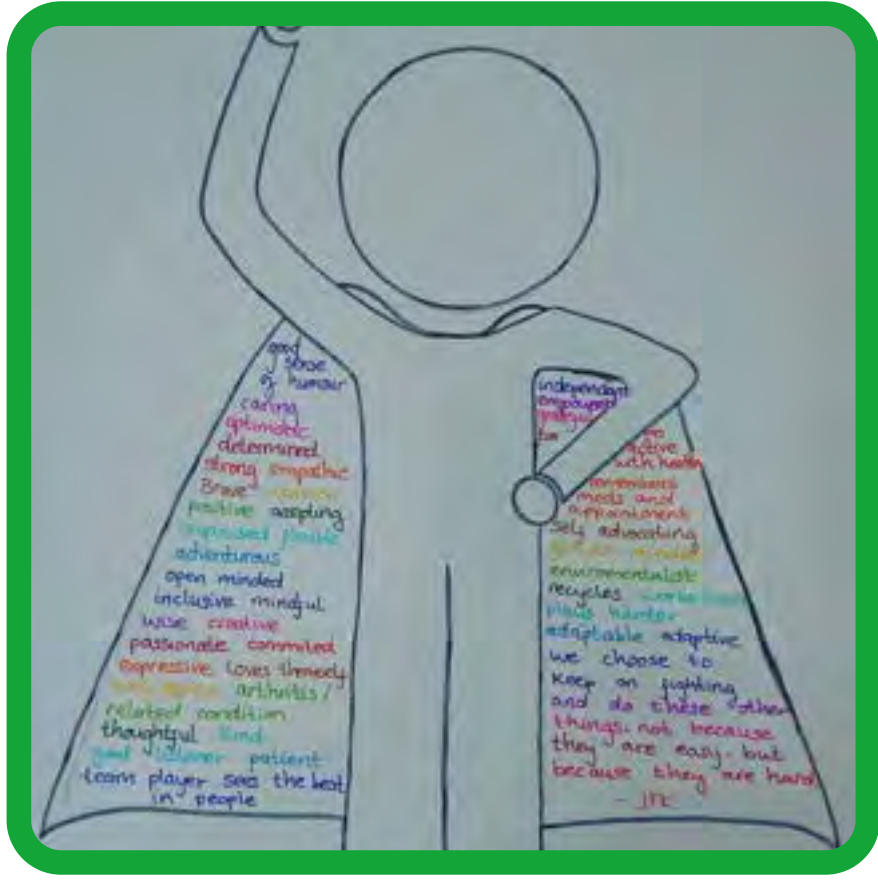


**Clinic Work**



**Areas where we  
support young people**





**VERSUS  
ARTHRITIS**

For more information please contact:  
[k.connor@versusarthritis.org](mailto:k.connor@versusarthritis.org)

 [YPFScotland@versusarthritis.org](mailto:YPFScotland@versusarthritis.org)

 [/TooYoungForArthritisScotland](https://www.facebook.com/TooYoungForArthritisScotland)

 [@YPFScotland](https://www.instagram.com/YPFScotland)

 [versusarthritis.org](http://versusarthritis.org)

Scotland Versus Arthritis  
Edward House  
199 Sauchiehall Street  
Glasgow  
G2 3EX

**SCOTLAND**  
**VERSUS**  
**ARTHRITIS**

