

# A Decade of **IMPACT**

10 Years of Scotland's Self Management Fund



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# Foreword

In the last ten years Scotland's Self Management Fund has enabled the development of projects, both large and small, that support people living with long term conditions to access information and develop the skills they need to live their lives well, on their own terms and with whatever health conditions they have.

The tenth anniversary of the fund is an opportunity to reflect on all of the successes the fund has achieved to date.

The Fund, which is administered by the Health and Social Care Alliance Scotland (the ALLIANCE), was introduced to provide third sector organisations and partnerships with an opportunity to develop and strengthen new project ideas and build upon existing approaches to support people with long term conditions.

It was introduced after our self management strategy, 'Gaun Yersel', set out the key drivers for change that would enable people living with long term conditions to live well – and on their own terms – with whatever conditions they have.

Since then, the Scottish Government has provided around £18 million, through the Fund, to support the development of 272 new ideas and projects the length and breadth of Scotland.

I'm delighted to see the progress of the projects

funded to date along with the diverse range of long term conditions they address. Projects that support people living with a wide range of long term conditions from chronic pain to sensory impairment to those recovering from stroke. It's also inspiring to hear from the people whose lives have been enriched through these projects.

The Self Management Fund has supported some really innovative initiatives which are helping people with long term conditions live their lives to the full. I am proud that the Scottish Government has supported these, and I look forward to seeing further innovation supporting even more people in the years to come.



**Jeane Freeman, MSP**

Cabinet Secretary for Health and Sport



# Facts and Figures over 10 years

**272**  
projects

Self Management Fund Round **81**

**30** Self Management Development Fund

Self Management IMPACT Fund **95**

**38** Transforming Self Management in Scotland Fund

Working Together to Strengthen Integration **28**

**210,271**  
People Reached



**285**

Jobs Created



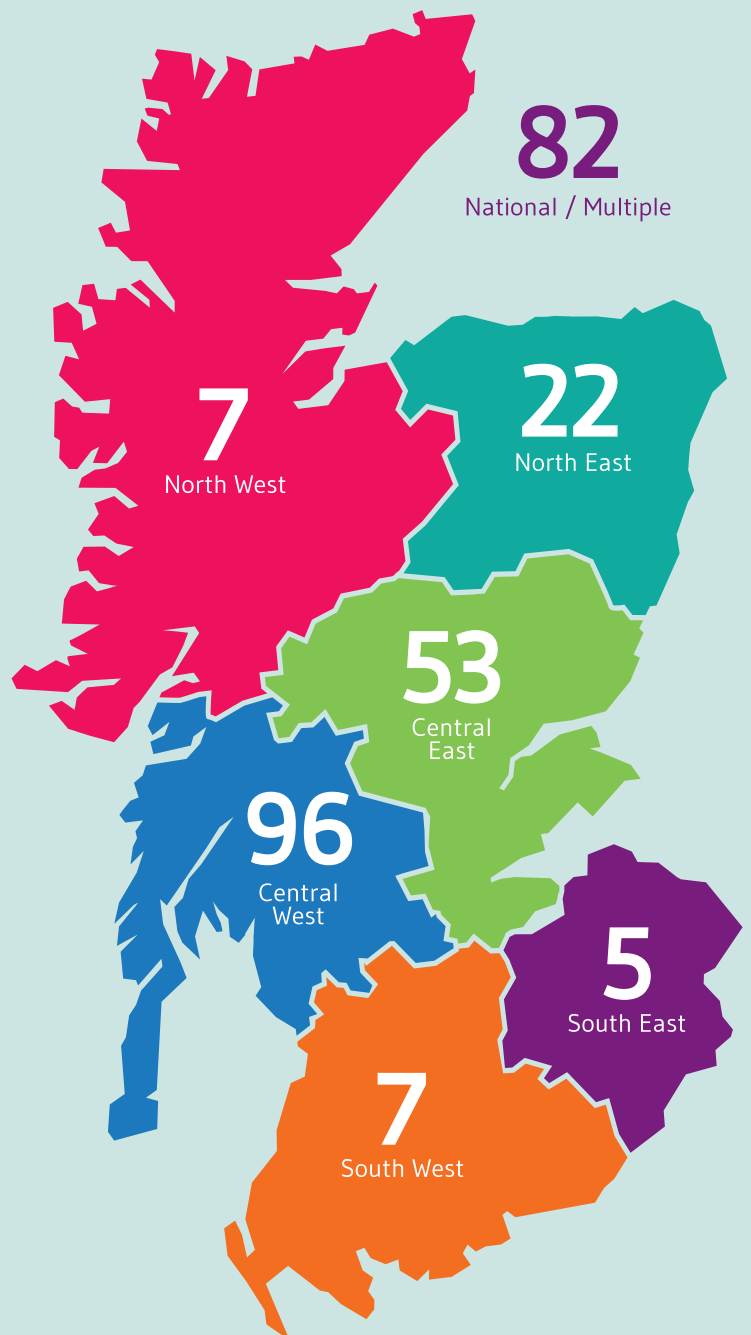
**1,752**

Volunteer Posts

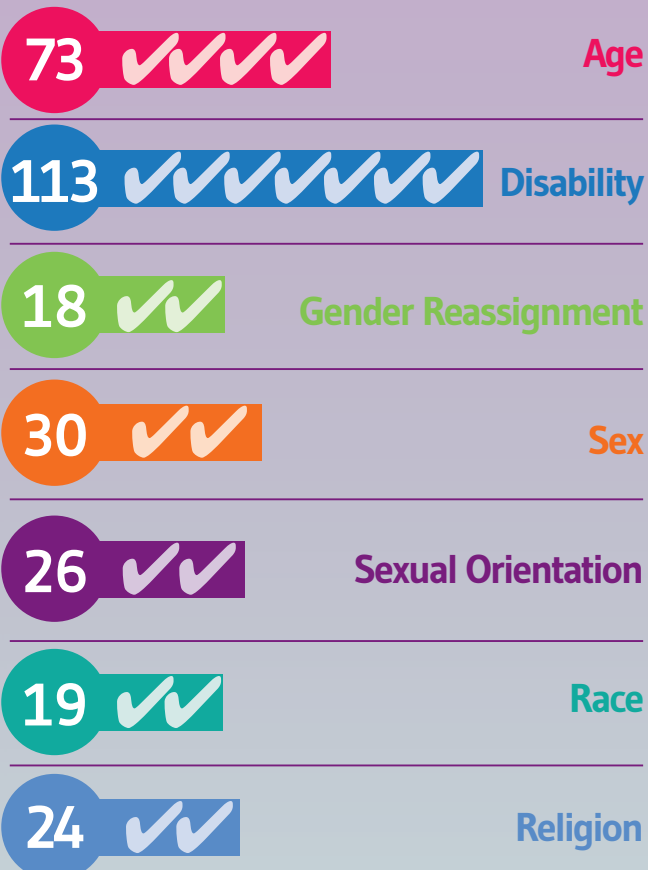




# Areas of delivery



## Equalities



# Design and Development of the Self Management Fund for Scotland

There was great excitement when the Self Management Fund for Scotland, a clear recommendation of the Gaun Yersel strategy, was to become a reality. A fresh, new fund dedicated to supporting and challenging Scotland's innovative Third Sector to define, redefine and keep on defining what 'self management' meant for people living with long term conditions, and their unpaid carers, in Scotland. A new fund born from notions of co-production and empowerment where people living with conditions were recognised to have unique expertise and insight into community-based solutions that would not only help themselves, but others too. A new fund administered from the heart of the sector itself, from a new organisation, the ALLIANCE, with a new strategic partnership with the Scottish Government, NHS and Third Sector organisations large and small, all over Scotland.

The temptation to rush to set-up the Self Management Fund for Scotland was great. When I joined the ALLIANCE in 2008 there was a great queue of people keen to take the annual allocation of two million pounds straight from my hands. There were great ideas floating around of where the money should be best invested, what the priorities might be and who might be best to shine a light on the future of self management. It was understandable. So many passionate people, carers and organisations had been involved in Gaun Yersel and therefore proposing the Fund. So many different ideas. So many different areas. So many different priorities, all converging around, and agreeing upon, the importance of self management, co-production and co-design.

Mirroring the values and intentions of the Fund itself, we set upon a period of engagement with stakeholders all across Scotland, finding out what people wanted to see specifically from the Fund. What would be useful, what wouldn't be and what would be supportive for the ALLIANCE to provide in terms of resource. Travelling across Scotland, meeting individuals, groups and

organisations to discover what people wanted was refreshing.

Co-designing the criteria for funding; the style and type of support that would be available; the application process and forms; the evaluation and monitoring expectations and also building in opportunities to celebrate the achievements and successes of individual projects enabled the ALLIANCE to deliver a new kind of fund. However, we didn't stop there. Regular reviews allowed all aspects of the Fund to be refreshed, re-focused and re-aligned to shifting strategic priorities as well as shifting expectations of those applying. We were learning all the time, and applying that learning. Understanding of self management changed too. The innovation which the Fund has enabled ensured that the innovative nature of the Third Sector in Scotland was not only reflected but also embraced to support the transformation of self management in Scotland.

Reflecting on the first ten years of the Self Management Fund for Scotland shines a spotlight on so many fantastic individuals, projects, organisations and collaboratives. The excitement that emerged ten years ago has not diminished. Long may that continue.



Kevin Geddes

# The Self Management Fund for Scotland

## In Perspective

**'Yesterday, I was clever, so I wanted to change the world. Today, I am wise, so I am changing myself.'**

*Rumi*

In this, the tenth year of the Self Management Fund we celebrate the progress that has been made across Scotland in the development of self management approaches led by people with long term conditions and their unpaid carers.

In the last ten years the Fund has been a catalyst

for testing, implementing and learning about self management through a combination of grant aid and support for organisations to share and learn.



The continued investment of the Scottish Government in self management approaches across Scotland has allowed over 270 projects to deliver a wide variety of support to enable people to be in the driving seat of their life with long term conditions or as an unpaid carer and the key principles developed then remain relevant.

## Principles of Self Management

**"Be accountable to me and value my experience"**

Evaluation systems should be ongoing and shaped by my experience. They should be non judgemental and focus on more than medical or financial outcomes.



**ALLIANCE**  
HEALTH AND SOCIAL CARE  
ALLIANCE SCOTLAND  
people at the centre

**"I am the leading partner in management of my health"**

I am involved in my own care. I, those who care for me and organisations that represent me, shape new approaches to my care.

**"I am a whole person and this is for my whole life"**

My needs are met along my life journey with support aimed at improving my physical, emotional, social and spiritual wellbeing.

**"Self management is not a replacement for services. Gaun yersel doesn't mean going it alone"**

Self management does not mean managing my long term condition alone. It's about self determination in partnership with supporters.

**"Clear information helps me make decisions that are right for me"**

Professionals communicate with me effectively. They help ensure I have high quality, accessible information. They also support my right to make decisions.



## Building the Narrative

With the focus on ensuring that people are involved in the design, delivery and evaluation of projects, this style of funding has lent itself to a wide variety of funded approaches in all parts of the country - Stanford Model courses, drama and performing arts, holistic therapy projects, recovery activity, independent living, digital applications and many more, all promoting and demonstrating the importance of self management.

The impact that projects have on the lives of those involved is clear, with people engaging in activities where they have not previously found statutory sector support that suits them and peer support consistently emerging as a key theme of self management support, whether this was an intended outcome or not.

When the Self Management Fund was first opened as a recommendation of 'Gaun Yersell': the Self Management Strategy for Scotland, there was no developed narrative about the significance of self management in a progressive health and social care system in Scotland.

Ten years on from its inception, however, knowledge and understanding about person-led approaches to self management has been so well promoted through the Fund and the Scottish Government's drive towards citizen-focused policy and practice that it is now reflected as a priority in every health and social care policy and strategy produced by the Scottish Government.

The Quality Programme, the National Clinical Strategy, Realistic Medicine and the Digital Health and Social Care Strategy are all built on person-centred approaches and the development of supported self management.

## The Importance of Integration

Underpinning these strategies has been the delivery of Health and Social Care Integration, the most extensive piece of service reform since devolution.

Importantly, the process of health and social care integration is about far more than managing financial or demographic pressures; it's about relocating people to the centre of service delivery, treating them as active citizens who contribute and enjoy the right to live high quality, independent lives in which they are in control.

Since integration came into force we have seen a significant shift in the public sector landscape, structures and staffing, with a drive towards the involvement of people in service design. With over 11,000 third sector organisations in Scotland involved in activity relating to health and social care, these organisations are an important part of the integration picture

Integration remains a radical opportunity to reshape culture and practice but only if people who use support and services, and the third sector, are equal and active partners and Integration authorities shift resources, including the workforce, towards the kind of preventative and community-based approach that self management represents.

The publication of the Audit Scotland Update on Progress report at the end of 2018, followed by the final report from the Ministerial Strategic Group in early 2019 has highlighted the need to address several issues including commitment to leadership and relationships, sharing of information and learning, and meaningful and sustained engagement.

These are all areas in which the third sector can be key partners to support integration authorities to deliver strategic plans and provide seamless support for people living with long term conditions and their unpaid carers through self management approaches.

## Self Management Partnership and Practice

As the fund has developed over the past decade, interest in self management has seen a consistent increase across sectors and a consistent increase in interest in the Self Management Fund.

This correlates with an increase in expressions of interest in the ALLIANCE's self management work and requests for development support.

As a result, in 2014 the Self Management Partnership and Practice Programme, including the Self Management Network for Scotland (SMNS), was created to respond to the increased demand for support and information over and above that which the Self Management Fund team and funded projects could provide.

Since its inception, the programme and the SMNS have been supporting the sharing of learning and



development of self management approaches across the country and providing a range of opportunities for networking, learning and development.

Through this, we have seen an increased interest in collaborative working from public sector organisations, including health and social care partnerships, to developing and delivering person-led approaches to self management.

It is heartening to see this positive shift towards collaborative working with the third sector, a recognition of its strengths, its 140,000 paid staff, and its 1.5 million volunteers to lead and deliver engagement activities and community-based support.

As part of this process, the ALLIANCE has supported the development of a number of locality-based self management networks bringing colleagues together in a cross-sector format to discuss local provision and solutions, The further development of a Self Management Reflective Practice training course has facilitated this collaborative activity.

## Learning and Sustainability

In the past decade key themes and learning have emerged throughout the projects including sustainability, building trust, and peer support.

Sustainability is always a key issue with all projects due to the fluid nature of the funding landscape in Scotland's third sector.

When developing a service with people which will build their capacity to self manage long term conditions or life as an unpaid carer, it is clear that many approaches are useful for the long term, but are subject to the nature of relatively short term funding cycles and changing health and social care priorities.

As a Funder, the ALLIANCE supports organisations to approach sustainability in different ways, considering not only the continuation of projects, but by sustaining the learning from projects and implementing this throughout the work of other third sector organisations. Additionally, the promotion and development of partnerships with other organisations and sectors is a feature of the programme.

The development of resources which will last long past a funding cycle has been a key part of

many of the projects which have been awarded grants from the Self Management Fund. These have included development of toolkits so people know where to go at different points in their self management journey for support, resources to support people to have meaningful conversations as they come to the end of their life, and development of resources to support good conversations between people and their clinicians.

In 2016 the Self Management Fund, following a period of consultation, review and evaluation of the fund, took the step to trial-funding over a longer period, offering grants for up to five years (subject to continued funding from the Scottish Government).

Previously grants had been for up to three years in length, but what emerged from three-year projects was that, for some, the development of the projects with individuals, building trust and achieving buy in from other agencies took at least two years.

Therefore, as the three years came to an end, projects were only just beginning to feel embedded and developing clear learning about the activity itself, rather than the development. Consequently, it was decided to take the step to trial projects funded over a longer period, to learn about development, delivery and sustainability of projects.

Nine projects were funded over two phases of funding beginning in April and October 2016. All nine projects continue to run and their learning and development continues, with much of the learning reflecting the fact that projects more often than not, have to change and adapt to people's needs, as well as the local health and social care landscape.

One of the key pieces of learning around sustainability is that scaling approaches up isn't always the answer. Although we often see successful pilot projects going on to be 'scaled up' and implemented in other areas of the country, our project learning has demonstrated that what works in one area of Scotland, or with one community (whether that be geographical or otherwise) may not be suitable in another.

The key to 'scaling' ideas, is in fact to take the key elements and learning from a successful approach and adapt to the people and community where it is being delivered.

Flexibility is key, and this is particularly evident in implementing approaches in rural areas of Scotland, where there are unique challenges, including limited transport and slower roll out of broadband internet. Where digital could be most effectively utilised to support reduced isolation, and implementation of innovative approaches to health and social care support, it is often most difficult due to the lack of infrastructure.

### Building Trust

Building trust has emerged as a key piece of learning in the development and implementation of self management approaches, not only with health and social care professionals, but also with people living with long term conditions and their carers.

Our learning over the past decade tells us that it can take up to three years alone just to develop trust. Projects have found that it is always a 'slow build' and that they need to take the time with people to develop relationships and demonstrate their commitment.

The funding structures for the third sector have often led to a hesitancy from people living with long term conditions, their unpaid carers and people working in the statutory sector. For instance, a key piece of learning emerging from some of the projects funded over five years is that when implementing a project nationally, that time has to be taken with each area to listen to their concerns, hopes and adapt to this to ensure that a meaningful partnership is developed with the buy-in of all parties. This time is necessary to ensure self management activity is developed appropriately and in a way which is likely to be sustainable.

In terms of statutory health and social care partners, they are often so busy that there is a need to work with them to demonstrate what the third sector can do for them, to support them to support people with long term conditions to self manage without adding to their already high workload.

This inevitably means listening to the needs in different communities and adapting the approach to their needs, as what works in one area will not necessarily be successful in another.

For people living with long term conditions and

their unpaid carers, many have seen projects appear, working hard to develop support approaches and then disappear due to funding constraints, leaving communities lacking in a support which has been supportive and much needed.

Consultation and discussions with communities over the past ten years tells us that people are hesitant to invest too much of their time and energy supporting and/or taking part in activities where they feel that it may just disappear after a year due to lack of funding support.

Funded projects must carefully plan how they will work with and manage the expectations of communities regarding funding. However, by building this trust we often see some of the most innovative approaches continued in some form past initial funding periods.

### Peer Support

Our learning tells us that a key part of self management is being able to hear from and have discussions with others who have a similar condition or experience, and being able to share what has and hasn't worked to support the management of life with a long term condition or as an unpaid carer.

Without fail, peer support has come up in every round of funding as a key theme whether as an expected or unexpected outcome of projects.

Where projects have not focussed on peer support as the key activity, throughout the project lifetime, consistently people identify in feedback that one of the most useful and important aspects of projects has been the importance of meeting and hearing from other people who have similar experiences to them.

Where the funded project activity is linked to developing peer support approaches, the learning reflects this need, but also the need for structure for formal peer support approaches.

It has become clear over the past ten years that where peer support is the focus, a clear infrastructure and boundaries need to be in place to support all involved. Peer support is always valuable, but if it is to be effective people need to be well supported and current learning indicates that peer support projects are not an effective approach to sustainability if the assumption is that

people will voluntarily continue this support in a formal way without any support or supervision.

This learning is strengthened by the movement in Scotland across third sector organisations to develop accredited peer support training, and encourage organisations to recognise this as a specific, employable skill, which needs infrastructure around it.

We expect to continue seeing the growth of peer support as a theme and approach to self management across the country over the next ten years. However, the evidence continues to build for the continued support and supervision for formal peer support approaches.

## Facing the Future

When the Fund launched, £2 million per year equated to £1 per head for each person living in Scotland with one or more long term conditions, we now know that, according to the 2017 health survey, in Scotland 2,182,116 adults and children are living in Scotland with one or more long term conditions and over 750,000 people in Scotland are unpaid carers.

Therefore, £2 million per year now equates to only 68 pence per head investment in those people living in Scotland who can benefit from self management support, a reflection of the demographic and financial challenges we currently face across the range of health and social care services.

At the Self Management Four Nations Summit in Edinburgh in 2017, Derek Feeley, now Chief Executive of the Institute of Healthcare Improvement and former Chief Executive of NHS Scotland, said "The Self Management Fund was the best investment I ever made. It put the power where it ought to be."

Through investing £2 million annually into projects led by third sector organisations the Fund has supported 272 projects, all of which have demonstrated the importance and power of co-production in action and that putting the person at the centre is a keystone of success in supporting people to live their life in the driving seat whether living with long term conditions or as an unpaid carer.

In an average year, people with long term conditions spend 4 hours with clinicians and

in appointments with health and social care professionals.

This means that in a year they spend 8756 hours self managing, highlighting the importance of person-centred self management approaches which ensure people feel able to navigate those hours. In this context, the voice of lived experience is part of the key criteria for the Self Management Fund for Scotland and it is crucial to ensure that this part of our ethos is continually reflected in the work which is funded.

Scotland's National Clinical Strategy makes it clear that self management approaches are needed to support people to live well and to support the health and social care system in Scotland. Health and Social Care Integration provides us with an opportunity to embed self management approaches in the fabric of support for Scottish citizens living with long term conditions and as unpaid carers. This requires integration authorities to recognise, acknowledge and commission the expertise and flexibility which the third sector offers, an effective investment to provide consistent person-led support across Scotland.

The Self Management Fund will continue to play a key part in this, offering the opportunity for third sector organisations to innovate and develop co-produced approaches to self management which complement, support and strengthen the work of health and social care authorities.



**Professor Ian Welsh OBE**

Chief Executive,  
Health and Social Care Alliance  
Chair,  
Self Management Fund for  
Scotland Grant Assessment Panel

# The evidence of the fund's impact shows how much it has changed lives for the better in Scotland

As Scotland's Self Management Fund celebrates its 10<sup>th</sup> birthday, I would like to take this opportunity to reflect on the impact the fund has made. It has supported and encouraged us to access the information and to develop the skills we need to live life well, on our own terms, with whatever health conditions we have.

In 2008, Scotland published its first self management strategy 'Gaun Yersel'. The strategy set out what needed to change for those of us living with long term conditions. Co-produced with people living with long term conditions - coordinated by the ALLIANCE and working with Scottish Government - it initiated the discussion about self management in Scotland – what it looks like in practice, and what it means for core services in the health and social care system.

The following year the Self Management Fund was introduced, supported by annual funding of £2 million from the Scottish Government. The fund is managed by the ALLIANCE, who do an excellent job on our behalf providing grants – both large and small, – to third sector groups to encourage the development of new approaches to self management and the sharing of good practice. It is a unique opportunity for community and voluntary organisations and partnerships to develop and strengthen new ideas, as well as existing approaches to self management.

In the ten years since it began, the fund has supported more than 270 worthwhile projects across Scotland. These are projects that continue to support those of us living with a wide range of health conditions to enable us to live our lives well and on our own terms. All of the projects funded to date have the experience of people living with long term conditions – and that of their unpaid carers – at their heart.

In its first year, 16 projects were funded to

support people across Scotland living with health conditions ranging from asthma to neurological conditions. Last year 26 new projects received funding spanning even further across Scotland - from Dumfries and Galloway to the Highlands and Islands – supporting people living with a wide range of health conditions such as mental health conditions, lymphoedema and those affected by stroke to live their lives well and on their own terms.

The evidence of the fund's impact continues to demonstrate how much it has changed lives for the better in Scotland. Over the last decade it has championed a person-centred approach rooted in the belief that we are in the driving seat and can actively contribute to successfully managing our own health and wellbeing.

As I leave my post to a new role within health improvement at the Scottish Government, I look forward to continuing to support people with long term conditions manage their own conditions to enable them to lead longer, healthier lives.



**Liz Sadler**

Scottish Government



# Waverley Care



Waverley Care were initially funded through the Self Management Fund in 2009 to design, develop and deliver a range of self management programmes to individuals living with HIV and/or Hepatitis C across Scotland. More recently, the organisation received new funding in 2018 to design a bespoke self management programme for young adults aged 18-30 living with HIV. The focus of this new project is to provide support to young adults as they transition from paediatric to adult HIV care.

Waverley Care developed these self management programmes in response to the needs of people living with HIV and Hepatitis C. People using their services wanted a life skills programme that would support them to live well with their condition.

The people Waverley Care work with have a range of complex health needs around living with a chronic but highly stigmatised condition. This can have a profound impact both at the point of diagnosis and as they live their daily lives.

HIV and Hepatitis C related stigma can undermine people's confidence and skills; preventing them from moving on in life; leave them feeling socially isolated and excluded; fearful of their future; fearful of rejection and disclosing their status to others.

Many of the people who Waverley Care work with have low self-esteem and self-worth and experience multiple discrimination because of their sexuality, gender, ethnicity, or lifestyle. When faced with these challenges, people often find that their capacity to sustain independent living is substantially compromised.

The self management programmes over the last ten years have allowed Waverley Care to provide individuals with a range of techniques, skills and self management tools. It has enabled them to set achievable life goals, to plan for a better future and to live well with their conditions.

A real benefit of the programmes has been

bringing people together and connecting them into peer support; enabling them to share their lived experience and their own solutions.

The programmes are co-facilitated by peer mentors, who are themselves expert role models. Peer mentors have supported people who are newly diagnosed, helping them to address self-stigma and letting people see that they can live well with their condition.

Additional support was provided by ALLIANCE staff to develop and implement the initial idea of the self management programme. The ALLIANCE gave the organisation time to test and learn from the programme's delivery as well as share this with other partners. The Self Management Fund also provided training opportunities from Evaluation Support Scotland to evidence impact. All of this assisted in designing a programme that was responsive to the needs of the people who used the services.

The ALLIANCE were also key in connecting Waverley Care to other organisations who could share their expertise in various areas. This was vital in the early development of a bespoke self management programme to women from the South East Asian community, living with Hepatitis C. Waverley Care were signposted to Diabetes Scotland, who were already engaged with this community. They were able to provide Waverley Care with information to ensure that both the approach and the content of the programme were culturally sensitive to the needs of these women.

A highlight for Waverley Care came in 2015, when they won a Quality of Care Award for the self management programme, in the category of 'Best UK Patient Support Programme' for individuals living with Hepatitis C. The self management approach was recognised as a way of supporting individuals living with Hepatitis C to maintain and support people into their Hepatitis C treatment and clinical care.



# The Haven



With funding from the Self Management Fund, The Haven have developed a self management programme for people living with cancer related lymphoedema. After developing lymphoedema individuals are referred from their local hospital to the Haven – staff at the point of release and those fitting compression garments are aware of the Haven and are quick to refer.

The course is made up of 4 group sessions lasting two hours each and a one to one session with a lymphoedema therapist. As the vast majority of participants who are accessing the course have only just heard of lymphoedema for the first time, the course focuses on education. Course content revolves around understanding the lymphatic system, skin care, compression garments, exercise for the lymphatics, along with practical skills such as kinesiology taping and self-bandaging, and emotional wellbeing.

These skills help participants build resilience and confidence in managing flare ups of their condition when they arise in their daily lives. Simple actions that previously posed barriers such as carrying shopping are now possible. Peer support is an empowering aspect of the course, having others to go through the course with helping one another go through the different stages of recovery that each person was experiencing.

Participants are provided with a DVD resource that serves as a guide to doing compression bandaging at home which, along with exercises, are able to effectively improve flare ups.

Many participants have moved into volunteering roles at some time after having taking part in the self management course, and are now champions of the course who share their experience and with others looking to engage.

After having taken part in the course participants have then gone on to lead active lives whilst living with their condition. The course teaches them skills in balancing their hobbies and aspirations with recuperation and the self management techniques they have learnt.

The fund allowed The Haven to test and develop

ideas around self management and turn that into a course they could deliver. The two-year funding gave time to pilot, test and run the group. This gave them security and confidence to deliver the course as well as expanding to deliver a comprehensive program with a range of resources attached to it.

Having been awarded funding a second time has allowed a level of focus to be placed on the project that wouldn't have been able to happen if they were having to chase other streams. It has also enabled them to leverage in additional funding using the evidence from the fund to either maintain the core funding or build on what the course can offer.

The level of support offered has been a significant aspect of how the ALLIANCE works for organisations. Being able to have conversations with the staff upon initially applying is a collaborative process in terms of the guidance and advice that is provided. Being able to talk through ideas and perspectives of what self management means were very helpful. That





dialogue remains ongoing and provides a better focus of what will be delivered.

From a condition level, the learning has shown how vital it is to have an exchange of understanding with health professionals so they can spread awareness of the project and refer their patients on. It has also shown that people can make a difference in their lives and changing the perspective that there is nothing that can be done with the condition.

Listening to the clients has been vital around how they can further their self management and enable them to empower themselves and listening to their ideas to shape and develop their services.

Partnerships have been a strong strand of the work of The Haven. This has been helped vastly by being well integrated with health services and developing robust pathways to 'after care' services. The Haven is featured in Lanarkshire's Cancer Strategy and the lymphoedema self management project was actively promoted within the Living With and Beyond Cancer stream.

At The Haven centre in Forth there have been strong links developed with senior managers in

the local Health and Social Care Partnership to release staff to attend information sessions as well as Haven staff meeting with Integrated Care Teams to explain some of the work to them.

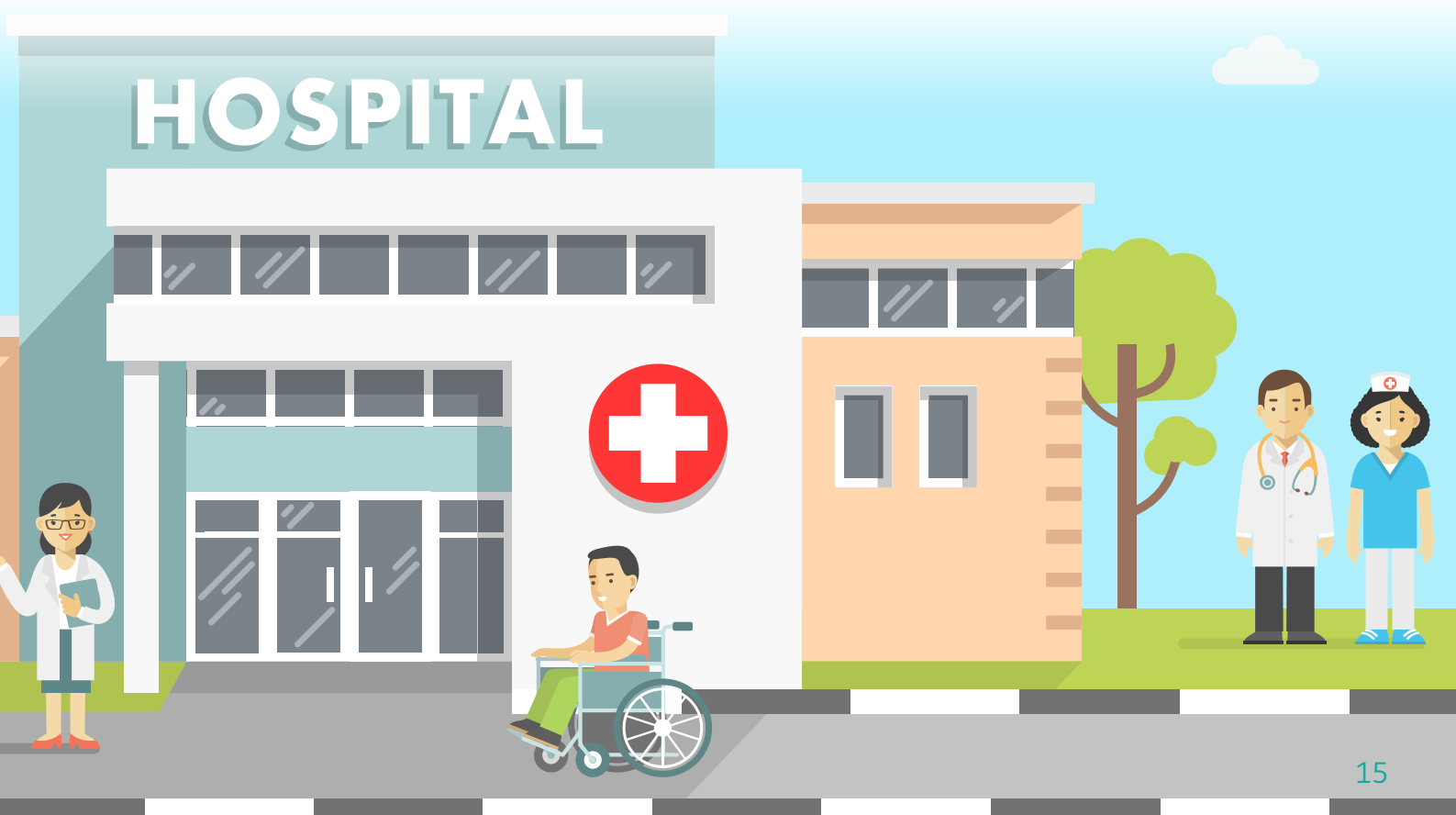
Links have also been established with third sector organisations such as Breast Cancer Care and also local community organisations to deliver talks.

Self management as an approach is becoming more understood and awareness is growing. There is an appetite to focus on preventative and early intervention measures, however, it seems that the good intentions are only that, when targets need to be met and the money still often goes to the other end of the scale. So it is an on-going challenge to ensure investment goes towards these approaches and resources. We are still missing that leap of faith from commissioners.

Being funded by the ALLIANCE has been immensely helpful above and beyond just the investment. In terms of being an excellent resource to pick up the phone and providing support as well as offering lots of opportunities to network and learn.



CASE STUDY



# Versus Arthritis



Versus Arthritis' Young People and Families Services, Joint Potential, works with 16 – 25 year olds who have arthritis or rheumatological conditions. It started by running self management residential weekends focusing on positive future, self-image and activity weekend. The project has expanded to deliver five residential weekends per year, three one day workshops and as a result of the Self Management Fund, the service has been able to develop even further by supporting the service directly in clinical settings. It has also provided the capacity for the project to meet with clinicians and give them the offer of being able to set up a clinic specifically for this age group who are transitioning into adult services. This provides the opportunity to link in with young people within the clinical environment along with direct contact through traditional activities.

The clinical aspect of the project was initially piloted in Fife thanks to a strong relationship with rheumatologist in that area. She had seen first hand the improvements in young people self managing their condition through attending Joint Potential activities. She had also noticed a shift was required to support those moving from paediatric to adult care to adjust to the difference in clinical styles. She pulled her patients who were transitioning between services into one clinic per month and created a specific space in the hospital for Joint Potential to have a room to meet with the young people individually while they were waiting. This allowed for drop in style conversations with young people to support them to prepare for their upcoming appointments with both paediatric and adult clinicians. Having the space in the clinic also allowed Joint Potential to meet with parents and carers, who were nervous about the transition process and give reassurance.

This approach provides value in being able to support young people to engage in the other activities the project has to offer as well as being recognised as an ally to the young

person. One of the strengths of the project too is that Joint Potential is recognised as being part of the clinical team with Honorary Contracts and SLA Agreements in place allowing Versus Arthritis staff to sit in on multi-disciplinary team meetings. Here they can input on their own assessment and influence the conversation. providing a different, youth-work orientated perspective rather than purely clinical one and also provides input on signposting resources and support that the clinical team might not have been aware of.



## CASE STUDY

Learning from the young people has shown that they appreciate having someone there who they can establish a relationship with that knows what having the condition is like and therefore bringing down their anxiety. Through improving their ability to self manage, Joint Potential have seen improvements in their confidence, and resilience. Spending time in clinics has seen a reduction in a young people's isolation through linking them in with the Versus Arthritis network and to peer support opportunities, skills development and personal development.

Clinicians are able to see the benefit of having Joint Potential staff on board as they have something to add and can provide a

more rounded view of self management. They are able to observe a more person-centred approach to engaging the young people and the different resources they will often point young people towards. They also see a difference in their patients once they have met with Joint Potential prior to an appointment.

The funding since 2016 has allowed that expansion into clinics but having it over 5 years has given the statutory partners, who are normally reluctant to work with short term funded projects, the security needed to work with Joint Potential. Health professionals



often don't want to send their patients to a service that may potentially run out of funding in a year. Momentum can be built with longer funding periods which is useful when working with the statutory sector as things can often take longer to develop due to the checks and balances of health and social care systems.

The ALLIANCE and more specifically the SMNS and funded project learning days has been highlighted as a key vehicle for support in bringing together funded projects. That support as a peer network of third sector organisations is invaluable.

The flexible nature of the reporting is forward thinking and also person centred because different methods work for different individuals and projects.

The Self Management Fund provides Scotland with a unique resource to support a Government strategy that is also unique to this country. It puts organisations in a unique position to then go on to support individuals to self manage with the backing of Government. It is something that charities should capitalise on and the time is right to push on with self management approaches.

Joint Potential, are also celebrating their 10 year anniversary in 2019.



# Thistle Foundation



Thistle Foundation's Veterans Project worked to develop a dedicated supported self-management service for veterans with long term conditions. Being personal outcome focussed meant the project engaged veterans who were marginalised from other services because they did not fulfil their required inclusion criteria.

Support was tailored to each individual and the process was steered by what the person felt mattered to them. Therefore the types of help could vary from practical advice for housing or benefits to signposting to psychological support through military organisations such as Veterans First Point.

Veterans could also receive reflective self management support in both one to one and group based settings. This gave individuals the opportunity to explore tools to self-manage and help them reflect on progress they were noticing from the changes they were making.

Another focus of the project was to promote peer contributions to the support veterans could receive. This led to the development of Veterans volunteers to assist in various aspects of the project. Six paid peer roles were also generated during the project. Each role had a different focus including marketing, creating a relaxation course, co-facilitating physical activity programmes and supporting Lifestyle courses off-site.

Using some underspend Thistle were able to provide a Veterans Men's Shed after this had been identified as a means to receive more informal support. The Men's Shed is located at the Thistle Foundation site.

Through the Veterans Project Thistle were able to

engage with over 100 veterans. The people that took part in the project noticed positive changes in their confidence and how they were coping. They felt more in control and gained new strategies to deal with situations. Generally, veterans believed meeting other people in similar situations was very valuable.

Despite being based in Edinburgh the Thistle Foundation made the project available to any referrals and made a concerted effort in its outreach work to engage veterans further afield. This was done through making connections with Poppy Scotland and Scottish Veterans Residents. This enabled the project to take its Lifestyle Management course to Inverness as well as Edinburgh.

Visiting places where Veterans attended was an important aspect in initially engaging with individuals. Similarly, having 'Veteran' in the title was an aspect that many pointed to as being a key driver in them accessing the service. Over the two years it was also noticed that many of the referrals were by recommendation of other veterans who had attend the project.

The Veterans Project was an important part in helping the Thistle Foundation develop the support it currently offers veterans to self manage and for some their transition into civilian life. The Men's Shed is still going strong and after six months following on from discussions with the Veterans they decided to make it an integrated shed open to all.



## NKS



The Nari Kallyan Shangho Self Management Project aims to build confidence among South Asians with long term health conditions to self-manage their health through tailored education and support to make informed decisions about their health and lifestyle. The project also aims to challenge the stigma in the community that leads to isolation among people with long term health conditions.

The self management project provides group advocacy and befriending opportunities for people living with long term conditions and carers. The groups provide a platform to share information about the needs and barriers of people in South Asian communities to manage their conditions. The project also holds a 'men's only' group that provides a space for men to support one another and reduce isolation.

Families of individuals living with long term conditions are also supported through several means to reduce stress, isolation and helping them to provide better care. Families can learn how to manage and maximise financial resources, explore avenues for building extra capacity for caring at home and build a foundation of knowledge around improving wellbeing through detailed information in their first language around a range of subjects, including about a person's condition.

These various strands of support from Nari Kallyan Shangho has been welcomed by the South Asian community thanks to its profound understanding of their cultural and social issues.

Individuals and their families now have a clearer understanding of their conditions which in turn has helped to manage these better. Many felt equipped to access other services should situations around their conditions arise and others have even been supported to go back to work.

Family carers are now empowered to take informed decisions with individuals having been on care assistant training or deciding to

go on carers breaks. Individuals report growing in confidence thanks to the support with some going on to take up volunteering roles and even employment on a sessional basis through Nari Kallyan Shangho.



The project produced several learning points around South Asian communities and how they respond to living with long term conditions. There is still a huge stigma attached to some conditions such as learning disabilities and mental health issues. The families are often not recognising such issues or not seeking support when facing these circumstances.

There is a pressing need to educate South Asian families about the relevant health issues and, how managing their health appropriately will improve their quality of life. Many are still not aware of their rights and range of services. A lot of communication is required to convince families about the benefits of respite for family carers, especially women, to reduce isolation and begin to work towards their own personal development.

Finally, we saw a great need for a support group for men as it has been identified that South Asian men often refrain from accessing services leading to them often suffering in silence.

The Self Management Fund has provided Nari Kallyan Shangho with the means to provide support to the South Asian community in varying degrees. Staff from the ALLIANCE have provided important one to one meetings to advise on any gaps and improving the development. An understanding of how community groups operate, and the challenges often faced by these organisations were regarded as especially helpful.

Future plans to build on the capacity of individuals and their families include developing the capacity of the staff and volunteers, providing one to one support and increasing the support and services to carers.



# My experience of Self Management

When I think of self management I think to my experience of a family member coming to terms with and adapting to living with long term conditions. This was a learning journey for us all as a family with the person with lived experience at the centre. This journey was about being flexible to discovering, researching, understanding and to applying and testing different things to make the best experiences possible whilst remaining resilient and in full control. As I reflect I think of the fun and laughter that contributed to the good times and to make the not so good times better.

My experiences informed my work, collaborations and networking to the self management work through the Long Term Conditions Improvement Collaborative and the development of the Self Management Strategy Gaun Yersel. The strategy brought self management to the fore creating the conditions for dialogue and actions promoting the person with lived experience at the centre underpinned by co-production principles.

Over the past decade my reflections are that there is a wider understanding of self management and implementation of person centred care though there will always be room for adaptability and improvement.

The development and implementation of the Self Management Fund has created opportunities for amazing initiatives rather like a pebble dropped in a pool with numerous ripples which have positive impacts on the person, their families and the wider communities. To me this is evidence across all communities and sectors of the increasing knowledge, understanding and implementation of self management, from sign posting for example ALISS, to Links Workers and Community Connectors, and the work of all voluntary organisations and sectors to the promotion, implementation and support for self management.

The contributions of the persons with lived experience, carers, families and volunteers are paramount for sustaining self management. These experiences are captured through feedback and stories from these initiatives and are testament to the impact that self management continues to have now and into the future. This rich feedback

supports and informs our learning, future directions and development of self management.

The collaborations and collaborative working of numerous voluntary sector organisations and across and with sectors and with people is a celebration of integrated care which spans Scotland wide and beyond.

The richness of the self management initiatives has informed the development and establishment of the International Foundation for Integrated Care (IFIC) Self Management and Co-Production Special Interest Group (SIG) which is led by the ALLIANCE and supported by [IFIC Scotland](#) and Moderators from across the globe. The SIG aims to facilitate collaboration across sectors and between Countries to enhance our understanding, adoption and evaluation of Self Management and Co-production. The SIG is for people with lived experience, practitioners, managers, researchers, students, policy makers and health economists.

My learning journey continues and I feel the future is bright if we continue to build and improve on our self management experiences and learning and not forget all the acts of kindness that contribute to this.

The web link for the Self Management and Co-Production SIG:

<https://integratedcarefoundation.org/ific-scotland-3>



**Mandy Andrew**

European Joint Action on Frailty

# Creativity At Home

Creativity At Home was requested by people living with long term conditions, but finding it increasingly difficult to leave the home. The project is delivered in partnership by Creativity In Care, made up of art facilitators using an established model of connection, working alongside Befrienders Highland, a charity providing befriending across Highland, who train and support the volunteers. The project visits people's homes with creative resources to facilitate an uplifting experience that reduces stress.

The project aims to support self management by inspiring or rediscovering interests and passions that feel empowering. By being responsive to needs, the project also supports people to gain more confidence in influencing services or resources.

Although still in the early stages of delivery, the project has gone through a robust process of engagement and exploration to deliver close partnership working that works for staff, volunteers and families.

A volunteer befriender and creative facilitator go into the home and take time to explore with the person the direction the creative experience will take. The team have a range of activities for individuals to gently try out and plan creative developments together. This might mean simply improving artistic skills or bringing something to life through story-making.

To enter a person's home to deliver a service was recognised as an area that would need to be navigated sensitively to avoid unsettling people. A steering group was formed with families who had lived experience. They shared what might cause stress with having someone come in to their home. This information was vital in preparing the project facilitators.

The sensitivity around going into another person's home is why the partnership was necessary. Creativity In Care could provide a focus on creating a valuable experience

for the participants and Befrienders Highland could bring their expertise in creating a safe environment for the facilitators.

In order to build a working partnership both organisations needed time to understand each other's worlds. Differences were overcome through open and frank conversations. Being given the time to understand one another and have those conversations were a valuable aspect of the funding.

Learning from one another has been recognised as being an extremely valuable aspect of the partnership. Creativity In Care have seen how initial training can be streamlined through observing Befrienders Highland training modules. Likewise, Befrienders Highland have found new strategies to establish connections with individuals as well as looking into designing possible delivery models over a set period as opposed to the open-ended befriending model which is currently used.

Creativity In Care highlighted a key strength of the Self Management Fund was the inclusive nature that allowed more people to be eligible for the Creativity At Home project. It was noted other funding streams had set criteria that excluded people who may be in need.

The Fund is refreshing in not making the project report on lots of data points and rather focuses on the key learning. It was noted this would allow for much richer information to be gathered that perhaps otherwise might have been overlooked or missed.

Creativity At Home is continuing its engagement work with a number of individuals and working to sign up more. Families from the steering group are continuing to guide the project to develop and improve how it interacts with people in their homes.



# Realize Your Potential

Realize Your Potential - QUEST is a self management program which inspires, supports and enables Young Adult Carers to realize their own unique potential.

The project's activities give Young Carers an opportunity to take some quality time out to look at; where they feel they are in life, what skills, talents and qualities they have, what they would like to do and how to get there and also how to overcome challenges that can often get in the way.

Realize Your Potential work in partnership with Carers Trust Scotland to connect with Carers Centres and Young Carer services across the country. Young Adult Carers consistently say in consultations that they feel too old or mature to be classed as Young Carers but equally they don't see themselves fitting into the category of Adult Carers. This has been one of the main drivers of the project providing much needed activities that this age group will easily connect to and identify with.

Upon accessing the self management course young people will start to move through a 30-hour programme that builds on helping them to see a brighter future for themselves and to inspire them with the action they can take to get there.

The project introduces the idea of Howard Gardeners multiple Intelligences which helps young people recognise that intelligence can take many forms. Individuals can finally see the potential within themselves and realise excelling academically isn't the only way a person can be smart. Activities such as working with artists to create vision boards support this idea and allow the young people to capture aspirations and passions they would like to pursue in the future.

The program also introduces strategies and techniques such as visualisation, relaxation and positive affirmations to help them better self-manage within their caring roles. External agencies are also brought in to deliver additional pieces of training such as Money Matters or public speaking to further build confidence in key areas of their lives.

Having gone through the core programme, a basic leadership skills training course (Train to Sustain)

is available to sign up to. During this course individuals can build on what they have learned through the programme and at the end of the training, assist the staff in delivering an activity to their peers.



CASE STUDY

Young people who have completed the course, many of whom have not previously engaged in any other activities, have reported feelings of increased confidence, self-esteem and belief in their own ability to achieve. Many of them have improved their social skills, made new friends and created strong peer support networks which they continue to engage with over and above the Quest programme. Some individuals have since gone on to pursue higher education, others have taken up leadership roles within the group and some have achieved SQA qualifications as a direct result from the program.

Some of the key challenges have been finding ways to initially engage with Young Adult Carers, this is due to general lack of confidence, self-esteem and the increasing level of mental health issues that many of these young people face. Often, individuals require extra 'hand held' support and encouragement to help them to take that first step in participating in a new activity such as Quest.

The funding has been key in finding solutions to the challenges that Young Adult Carers face. The Self Management Fund has provided Realize Your Potential with the flexibility to rearrange budgets based on the scale of need for each Carers Centre. More widely, the fund has provided the assurances needed to the centres' umbrella organisation Carers Trust Scotland to deliver a quality programme and add to the capacity of its centres. Most importantly, it has given the project space to test, develop and build trust with both the Young Adult Carers themselves and with the staff within the Carers Centres.

Momentum for this project has been gathering for a long time and with the consistent positive feedback being received, Realize Your Potential is determined to expand the Quest programme into other areas across Scotland.

# LGBT Plus



LGBT Plus aims to give individuals ownership of their own destiny through taking a holistic approach in the support they provide. This means supplying its participants with the skills and resources to successfully manage their conditions whilst also working with community and statutory organisations to find solutions to make that as easy as possible.

After engaging with the LGBT community throughout Dumfries and Galloway it was identified that the rural nature and sparse transport of the area meant individuals often struggled to attend activities held centrally in Dumfries. There was also a hesitancy to access statutory services through fear of outing themselves to their local community.

The project began holding themed self management meet ups around various conditions such as diabetes, obesity or heart conditions. These meet ups would include workshops or activities on how they and the various issues that can follow, such as loneliness and isolation, can be counteracted. These could take the form of CPR, first aid, walking groups, art or peer support. Participants could also be signposted if they needed additional support. This would be done by self management support workers who would also help in building up confidence and self esteem to be able to connect with the organisations.

The second aspect of the project became about engaging with statutory and community services to suggest ways that make it easier for people identifying as LGBT to access services. Awareness training has been offered to the likes of the police, fire service, GP surgeries and housing providers. A direct response to this has been to amend many of their processes and procedures. These can take many forms such as placing literature in waiting rooms and receptionists wearing rainbow lanyards. Seeing this allows people to feel at ease and open up about the various circumstances in their lives.

LGBT Plus have also partnered with other third sector organisations such as Sexual Health. They offer a discrete by post service for people

requiring condoms who don't feel comfortable or can't afford going to a clinic or pharmacy. A similar service is also available for the testing of STIs. The project is also working with Macmillan to develop solutions that help trans people discreetly present themselves for the necessary screening without feeling uncomfortable in the waiting room.

Participants of the project have shown an increase in self esteem and confidence. Many are now able to walk into doctors surgeries and express their needs or concerns. Some have also moved on a pathway to volunteering with LGBT Plus and running the outreach stands at community events.

The project has had feedback from statutory services including doctors who appreciate individuals now being able to better communicate their needs. Services now also have LGBT champions who go beyond delivering talks for groups to make engagement more than a tick box exercise and more about a partnership.

Two key pieces of learning centred around the importance of listening to the feedback from participants in shaping the project and the slow process that is obtaining buy in of LGBT friendly measures from statutory services. Many professionals and managers do not realise that there are measures which they can take.

The Fund has allowed for a support network to be developed initially from the staff from the project but has spread through volunteers and peers. The holistic approach to the support available to individuals empowers them to go on and become advocates in their own communities.

Last year LGBT Plus held a DG Pride event that brought together the whole community to celebrate LGBT Pride. Every statutory service in the area hosted a table at the event.



# Humans of Scotland



Humans of Scotland is the ALLIANCE's storytelling initiative that shares the experiences of those living with long term conditions, disabilities and those who are unpaid carers. Martin has been involved with one of our funded projects at North West Recovery Communities in Glasgow and tells his story of recovery from heroin use and how he now helps others on their journeys.

## Martin's Story

I was going through a trauma and my family was breaking apart. I was introduced to heroin. The first time I tried it I was injecting it and it was an overwhelming feeling of bliss. It wore off and I had to take more. It got to the stage I was taking it to feel normal – I wasn't getting stoned. I needed more and more just so I could function like a human being.

It got to the desperate stage where it was either suicide or trying to get help. I went to the doctor and he sent me to the methadone clinic. He told me I'd be on it for the rest of my life. I believed him. The methadone took away the withdrawals, it basically saved my life.

I got not well, and I was taken into hospital and I was told I had Hep C. I realised I didn't want to die without fulfilling my potential and getting recovery. I was taken to Addaction. I grabbed onto every bit of knowledge. I realised I could get recovery and I could make changes to my life. I needed to find purpose and I found purpose in recovery.

It took me two years to come off the methadone, I was on it for ten years. I gave myself hope. One of the fears is relapse. I had to put things in place to give myself the best chance, so I got involved in building the recovery community. I beat the Hep C. I started building a life for myself.

When I came off methadone, I heard horror stories about withdrawal. But it didn't happen. I wanted to tell everybody that it was possible, and it isn't a life sentence being on methadone.

I realised I was able to speak out about recovery. I had a really strong message. I've been a volunteer for six years and I've been able to help people.

I saw a change needed to be made in society regarding stigma and misconceptions about addiction so I've actually made a huge contribution along with other volunteers by promoting recovery in the media.

You can change your life, no matter the obstacles or the barriers, or how much despair you're in or how much you've given up on yourself, or how much the world's given up on you. You can change and be a productive member of society.



Martin Duffy

# Strathcarron Hospice



With the Self Management Fund Strathcarron Hospice wanted to find ways for people with long term conditions who are approaching end of life to be able to self manage.

There were three stages to the project: asset mapping, consultation and co-designing services. Challenges occurred in the project during the consultation period, as understandably people found it difficult to open up about their own end of life.

Large scale engagement was carried out involving around 400 people within the Hospices catchment area. Through analysis of the answers provided, some key themes were drawn out. These themes were reviewed and agreed upon by a participant group that was formed to partner in the co-design process.

The two key themes to come from this were that firstly, people living with a long term condition whose health was beginning to deteriorate, are able to carry on living their lives. Secondly, the main barriers individuals and their loved ones faced in making plans end of life plans were not knowing where to start in making plans, and feeling isolated by not having a non-family member to discuss their end of life who they didn't feel daunted talking to.

Two working groups were established to develop solutions to these key themes. This process was emotionally taxing for its participants who were providing or listening to accounts of lived experience.

Access to information became a central issue concerning how to address the two themes. Pop-up information stands were identified as an effective solution to ensuring people were getting the information that the working groups felt was needed. Upon agreeing on this output, the group shaped the critical details of the stands such as what information was helpful, where and when would be optimal for people to access the information, and the format for how it should be communicated.

Information stands, many of which were staffed by the volunteers from the participant group, could be found across the community in key locations such

as GP surgeries or more discreetly in community events. People would be given the chance to browse the information as they please whilst having the option to chat to a volunteer. The volunteers at the stand are people with lived experience and can relate to how difficult it can be having conversations about plans for end of life with loved ones. They can also relay their own experience of how positive it is to eventually have these talks with the people they care about.

The impact of the information stands has caused ripple effects into the local communities. Volunteers now act as ambassadors, in where they live for thinking ahead and making plans for the future. They continue to support each other as friends and many are still active in operating the stand. In the wider community, individuals have reported back about now having the confidence and knowledge to access support. There have also been examples of intergenerational support, as younger people looking to learn more about making end of life plans have spoken to volunteers at the stands.

The information stands still operate within the Hospices local community today, but it is the time they were given to carry out the consultation and engagement work that is highlighted as the most important learning from the funding.

Rather than expecting an output to be produced at a certain time, staff from the Self Management Fund encouraged project leads to continue the consultation and co-production process. This allowed the project to further explore the issues coming up and switched the staff's mentality from being solution focussed to a focus of genuinely listening and allowing the individual to come up with a solution that will work best for them.

As a direct result of the evidence produced towards the effectiveness of their engagement work with communities, Strathcarron Hospice have been able to secure further streams of funding. This has allowed the Hospice to work on other issues that had come out from the initial engagement group of the SMF project.



# Ayrshire Community Trust



Ours was an innovative project engaging with people with long term conditions who volunteered to support other people with LTC as a way of helping them come to terms with their diagnosis and help them lead as normal a life as possible. We recruited several volunteers who undertook training and were then able to support other individuals at diagnosis or at a time when it was appropriate for them.

The application process was very supportive

with staff from The Alliance helping us every step of the way. Once in receipt of the funding we were given opportunities to meet with other funded projects and offered support in evaluation processes. A major strength of The Alliance was the level of flexibility and understanding that things can change from writing the application to implementation.



# Borders Carers



Staying Afloat was developed by Borders Carers Centre and a local psychologist to provide a self management course to family carers to build up their own resilience and coping strategies to manage their own health. This in turn would mean they can better support the person they are caring for.

A scoping exercise was initially carried out to see what would work best for carers.

The course took the form of weekly sessions over the course of 6 weeks along with a follow up session. It was the first course of its kind to be run over a full day meaning facilitators were able to take a more in depth look at the issues affecting the participants. This allowed discussions to be much more well-paced and gentle.

The name of the course was also decided by carers and eventually changed from 'Float' to 'Staying Afloat' because it was felt that as family carers they would never really be able to float but this course might give them the skills to keep their head above water.

Each week the facilitated sessions would build on areas of the carers lives where they had indicated their needs were not being met. This could be focussed around a range of topics from empowerment, privacy, nutrition etc. Ultimately the carers would decide what was important to their wellbeing. Then they would plan how they could address this whilst considering their caring situation.

Every week would consist of group exercises, paired exercises and homework that would consist of achieving a manageable, bitesize goal to bring to the class for next week to reflect on the difference it had made. An example of this was taking 5 minutes, sitting quietly and doing breathing exercises, or going for an hour long walk.

The individuals were given a folder to take home with them to store various resources that provided information on a range of topics. The aim of this and the various exercises was to build up their own self-awareness and encourage self-care.

As the course progressed the levels of participation

in the course increased as did participants overall mood. Feedback from individuals would be collected weekly. Comments mentioned how they enjoyed the class, found peer support, received help in planning experiences and it helped them open up. Participants were encouraged to be as honest as possible in their feedback and staff pointed to many of the criticisms received as being key in shaping future courses.



Lunch groups began occurring outwith the course and friendships were developed between people who previously did not have any. Individuals have also taken up hobbies or volunteering in areas they were passionate about. Others have signed up to respite that they had never taken realising that to be able to care to the best of their abilities it is vital to maintain their own health.

Seeking out the views of family carers at the beginning of the courses development was key in setting in place the necessary measures to allow carers to attend. This was sustained through having the funds to provide adequate respite and expenses that gave participants the security to make it along each week.

Sourcing the appropriate staff was also central in properly facilitating the course. Having someone with a background in psychology meant there was an expert present to be able to navigate the difficult conversations that arose. A Support and Liaison Officer was able to provide any follow up support to participants following a session along with carrying out the various administrative duties.

Staying Afloat is still running to this day after its initial success.



# LTC Hebrides

Long Term Conditions Hebrides became a constituted voluntary organisation in May 2018 after a short term funded self management course that some of its future members attended came to an end. Having no other resources to adequately maintain the necessary support needed to self-manage their conditions they decided to take matters into their own hands.

Upon successfully attaining funding from the Self Management Fund the group began consulting with other residents from across the island about what would provide them with the best support.

The feedback they received was to run weekly gatherings that had a mix of self management skills training, mindfulness and relaxation sessions, and chair yoga to be delivered by the group's facilitator.

Participants of the group are mainly made up of residents from the Isle of Lewis with a mix of experience self managing a long term condition. The peer support that members can provide because of this is invaluable. So much so that simply attending the group regularly is an important strategy for their self management. A WhatsApp group is used for members to continue that support externally. Digital outreach is further extended using a closed Facebook group where useful online resources can be posted along with organising other activities.

LTC Hebrides use traditional General Practice methods to measure anxiety and depression levels along with a bespoke self management questionnaire which asks participants to benchmark their scores on a range of topics. This starts at the point of accessing the group and then measured throughout the course of their involvement. The levels of encouragement individuals get from the group has boosted positivity that they are making progress, people are coping better and reducing their anxiety levels. They are managing their lives better through being kinder to themselves and giving permission to say yes to things but also say no.

Relaxation sessions have been shown to reduce people's chronic pain, giving some participants

pain relief that they had not experienced for years. They have been able to transfer the learning they take from groups and apply them to their own lives and the lives of their loved ones.

CASE STUDY

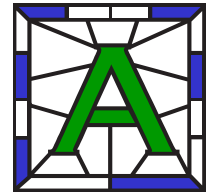
Learning and development has revolved primarily around how the group operate as a constituted body. As all the committee members live with long term conditions the structure has required to be fluid and members are able to cover in the duties for others who may not be managing well at that time.

Capacity of the group in general is a large factor in how the group runs. Getting to and from the group can be taxing for individual's energy levels. Going on an overnight mindfulness retreat proved particularly challenging for everyone involved. Both aspects highlight the precariousness that having a long term condition puts on things.

Key areas of the support received from the Self Management Fund have been the availability to have informal conversations and catch ups with ALLIANCE staff about the direction of the project along with development days facilitated by Evaluation Support Scotland. The days provided invaluable training in improving reporting procedures to the fund as well as providing the opportunity to learn about creative ways to produce it.



# Lomond & Argyll Advocacy Service (LAAS)



Lomond & Argyll Advocacy Service's (LAAS) Independent Advocacy project is about ensuring people who have a long term condition have access to an independent voice, which supports and enables them to feel empowered, valued, explore options and choices, consider self management options and have control over decisions that affect them.

We have been able to assist people who have been struggling with a variety of issues to address and resolve them. This may include supporting people who may have felt overwhelmed or excluded from decisions about their care and support, assisting people who have felt lonely, isolated and detached from their communities due to their illness or disability and helping people to look at ways of self managing their health conditions such as ensuring they have access to information and choices.

Having listened to the people about what they wanted and needed; the project worked with Community Education to create a Basic Self Advocacy Skills course. The desire for people to learn Basic Self Advocacy Skills has been described as inspiring by the project's staff. This course has been delivered to a number of people both living with and without long term conditions. The desire for Self Advocacy Skills demonstrates that people want to be able to self manage their own condition and have the skills that support them to do this.

The Lomond & Argyll Advocacy Service's Independent Advocacy project has allowed the organisation to increase the profile among a wider range of groups and individuals. Individuals who are most vulnerable, isolated, and unwell and may have felt excluded, have felt more involved and connected.

They have relieved some of the stress and burdens on the people living with a long term condition and provided additional support to the carer, family or support agency. Local people now feel more engaged with their community and with help have been able to access other services or local community groups they were previously unaware of.

Through the Self Management Fund LAAS have been able to reach out to a wider spread of community

groups and make connections with other services. The project has gone on to partnership with other agencies to develop Self Advocacy Skills which have been made widely available within the community, working with Community Education, Skills Scotland and Hope Kitchen (an Oban based Food Bank).

Through hearing about the work of the project other agencies that support people with long term conditions across Argyll have been in contact with LAAS requesting for the project to come and speak to people who use their groups and make referrals to the service. Joint working initiatives have then sprung out from these opportunities.

Feedback from many people who have accessed the project feel that LAAS' involvement has helped prevent a crisis arising. Many people say the service was crucial to them, along with feeling supported, valued and enabled to better manage their condition.





# Moray Wellbeing Hub



*Having been awarded funding from the 2018 round of the Self Management Fund, Moray Wellbeing Hub have now been funded twice. The first project funding from 2016 has been selected as a case study because this enabled the project to take its form as it is today.*

During 2016/17 Moray Wellbeing Hub project focused on harnessing the power of personal experiences to inspire more mentally healthy lives in Moray. This was enabled through a range of peer led activities including courses, arts events, group, consultations and more. These activities aimed to tackle the stigma surrounding mental health problems, increase people's access and awareness of self management tools, connect them with peer support and empower people to focus on their strengths and in turn empower others to do the same.

With the funding Moray Wellbeing Hub received, the project not only successfully supported local people with their wellbeing, but also built a legacy in creating a new social enterprise. Their work has been recognised as inspirational, not only locally, but nationally and internationally as a result. Inspiring fellow peer-leaders to learn from their journey and create their own local change to support self management elsewhere has been one of the main surprising results from receiving funding.

Through the Self Management Fund the project has been able to reach hundreds of people with peer led training and outreach, inspiring recovery by sharing stories alongside evidence based tools they can use to self-manage. People have felt more hopeful and connected as a result along with preventing medical treatment by taking better care of themselves and using peer support.

Partnerships were core to the initial self management project and the legacy of this has resulted in a sense of a wider team

in Moray. Individuals from across health and social care including public health, mental health services and more, work with Moray Wellbeing Hub on various events and activities alongside other third sector organisations and tsimORAY. National organisations such as See Me and Scottish Recovery Network as well as the ALLIANCE, continue to be connected in the work of the project. The key learning of this robust form of partnership working has been the values approach that has been adopted and Moray Wellbeing Hub's constant in their ask for co-production. The reaction to this has been that people have felt what that is like, and they want more of it.

Staff at the Moray Wellbeing Hub welcomed how the Self Management Fund encourages people with long term conditions to apply. On top of this they acknowledged their work with people who have lived experience and across the third sector to evolve future processes, radically year to year, as a result of taking a true coproduction approach. The project staff also found fellow peers in the Self Management Fund team who celebrated self management with them as well as holding them to account. The ALLIANCE's wider team also became critical friends, providing confidence, contacts and tools to embed their work locally and continue the impact beyond the year's funding.

The Moray Wellbeing Hub believe people need a lot of support in the modern world to think about themselves differently and be interconnected - to see their strengths rather than deficits, see their power as a community asset rather than negative labels linked to benefits and unemployment and pain management. Everyone in society benefits when they are all empowered and included.



# Write to Recovery

# Write to Recovery

The Write to Recovery project began as the online story sharing tool, a resource which helps people in recovery from distress and mental ill health to reframe their stories of pain and adversity, focus on strengths they have gained, and articulate their aspirations for the future.

The success and popularity of the website led to the creation of Write to Recovery groupwork, which brings this principle of solution focused creative activity to groups of people. The groupwork facilitates positive changes in its participants, providing space to build confidence and self-esteem, and take steps towards their self-defined recovery.

The Self Management Fund enabled Write to Recovery to extend its reach Scotland wide. It has added capacity to deliver the programme to a wide range of organisations and groups, and provide training to enable workers, volunteers, and service users to facilitate Write to Recovery groups independently. The Self Management Fund also enabled Write to Recovery to host local events, fostering the project's powerful spirit of community connection and self management.

Not only has the project worked with a broad spectrum of partners geographically, they have also brought the groupwork to spaces and venues not usually associated with self management and recovery. It became clear that the groupwork can be effective in diverse settings beyond the typical 'mental health' resources and that these settings might actually be most in need of this opportunity. These included universities, LGBT collectives, colleges, prisons, nursery school, churches, Scottish Government Civil Service, employability initiatives, and carers centres.

People who attended the groupwork achieved significant personal growth over just a few sessions. The Write to Recovery sessions at Strathclyde University for example, allowed the expression of difficult feelings like shame and low self-worth which are connected to distress

and poor mental health. By providing a protected safe space where students felt valued and listened to empathically, they are able to help and encourage each other to carve more positive, strengths based narratives and generate personal outcomes that they value.

These new perspectives and the growth in self-awareness seems to free up people to better self manage their distress and trauma. This group, as with others, highlights the way that Write to Recovery helps people connect not only to other participants but importantly with themselves.

People have become aware of inner resources and shift their focus towards their own self-efficacy from which springs realistic hope for a more positive and preferred future. Participants have reported that the groupwork has helped them overcome feelings of isolation and disconnection, substituting these with a sense of belonging and comradeship.

The key learning from the project has been that helping people to reframe their narratives in a solution focused way rather simply retelling their trauma stories, helps them to articulate resilience, skills, strengths and abilities they may have overlooked in the face of distress.

The Self Management Funds six monthly reporting process provides Write to Recovery with an invaluable opportunity for reflection, and to publicise the project in ever more creative ways. The ALLIANCE encourages new and creative ways of working and invites organisations to be imaginative in the promotion and application of self management skills.

There remains a great demand for Write to Recovery groupwork and its ability to support communities and individuals to build on assets and self management skills in order to reduce distress and enhance wellbeing and resilience.





# A decade of self management research – how the evidence base is shifting

Supported self management is increasingly being recognised in the current evidence base as a preferred term to refer to interventions and approaches that help people to develop the skills, knowledge, confidence, and resilience to manage the impact of their long term condition(s). This includes aspects of medical, role and emotional management, behaviour change, and the management of multiple morbidities. The term 'supported self management' represents a move away from traditional views of self management as being merely about education or compliance with professionally driven treatment plans and goals. Rather, supported self management focusses on the uniqueness of individuals' experiences and responses in managing their conditions, and supports them to live their lives in a way that is personally meaningful and purposeful for them.

The evidence base has shifted over the past ten years to reflect this; although there is still more to be done. Contemporary approaches and interventions to support self management are now embracing the idea of flexibility and tailoring to individual need rather than adhering to a model. Qualitative research undertaken over the past ten years has been hugely valuable for emphasising the individualistic nature of, and

the complexities that people face, in engaging in, self management and embedding this into the social milieu of their lives. There is still a lot that we do not know about, including how hard-to-reach and marginalised groups engage in self management and their preferences for being supported to do so. We also know little about how multimorbidities, low income, and health inequalities influence individuals' priorities for, capacity in, and contexts conducive to self management.



REFLECTION



Although the nature and scope of supported self management interventions in the evidence base are becoming more varied and creative, condition-specific and generic, structured programmes still dominate the research landscape. These have been shown to be effective in supporting engagement in self management and on a range of outcomes such as quality of life, self-efficacy, health-related behaviours, disability and function, and use of health services.

Over the past ten years, such programmes have evolved in their sophistication from simply focussing on education and information provision to incorporate a range of techniques

and approaches aligned with broader behavioural change theories and 'asset-based approaches'. In 2014, researchers at Queen Mary University of London and Edinburgh University published a report on self management interventions in people with long term conditions. The report showed that it is now commonplace for self management programmes to incorporate components such as psychological strategies to support adjustment and coping, practical support for activities of daily living, action planning and goal-setting, feedback and monitoring, and social or peer support.

Interventions that comprise such multifaceted approaches have been shown to be more effective than interventions that focus on education or confidence building alone. The evidence base, however, is stronger in some conditions, for example, diabetes, than in others. There is a wealth of evidence to underpin the DAFNE and DESMOND programmes, and diabetes self management is now an embedded feature of service provision in the long term management of diabetes and supported in national standards and guidelines.

More research is needed to evaluate the impact of formal and informal supported self management approaches to create and support changes in policy and guidelines, and in service provision and clinical practice across other conditions and specialities.

Evidence of effectiveness, however, is not enough to create and sustain change. We need more implementation research. Although, over the past decade, many supported self management interventions and approaches have shown positive impact, the optimal content, target outcomes, and mechanisms of change in supported self management interventions remain unclear. Although the concepts of 'minimally disruptive medicine' and 'Realistic Medicine' have been coined, we need more research to understand how to design interventions and approaches that minimise treatment burden, that offer meaning and value for individuals, and that can be easily integrated into their lives. Self management does not exist in a vacuum.

The evidence base has started to lay more emphasis on the importance of collaborative relationships and positive organisational cultures of support for self management. These concepts underpin the 'House of Care' model and align with recommendations from the evidence base that a 'whole systems approach' to supporting self management is required. We need more evidence on how different sectors can work most effectively together to deliver meaningful, sustainable and 'asset-based' supported self management services. Increasingly, we need a new approach that helps us to understand more about the conditions and contexts that makes supported self management work (or not work) in different communities and settings.

The conceptualisation and culture of supported self management in long term conditions has evolved considerably over the past decade; it is important that this is consistently mirrored in the developing evidence base. The evidence base on self management is rapidly growing in response to changes in policy and practice, and to address the needs of our changing populations. As supported self management becomes increasingly accepted and expected as an integral part of successful long term condition management, the priority for the research in the next ten years is to build on the learning about what works and what could be improved upon to ensure the transferability, sustainability and scalability of supported self management in service provision.



**Dr. Lisa Kidd**

# Humans of Scotland



Humans of Scotland is the ALLIANCE's storytelling initiative that shares the experiences of those living with long term conditions, disabilities and those who are unpaid carers. Michelle tells her story of managing her conditions and details how our funded project at Bipolar Scotland equipped her with the tools she now uses to live well.

## Michelle's Story

My health problems began back in 1986 when I was diagnosed with Type 1 Diabetes. I was in denial and rebelled against my doctor's advice but became extremely unwell and realised I'd have to make positive changes.

I struggled with mood swings and couldn't sustain a healthy routine. I became psychotic in 1991 after a miscarriage and was detained in a psychiatric hospital for four months. I was diagnosed with Bipolar Disorder and was in a state of emotional turmoil, powerless to do anything to help myself.

I struggled to cope and had another seven admissions to psychiatric hospital over the next ten years. My physical health deteriorated which led to kidney failure in 2004 and I was on dialysis for eighteen months. I was extremely lucky to receive a kidney pancreas transplant in December 2005 which had a very positive effect on my mental health.

A friend told me about Bipolar Scotland and we went along to the Lothian Bipolar Self help Group in Edinburgh. I found the peer support very helpful and we became group facilitators in 2010.

I took part in Bipolar Scotland's Self Management Training Course in 2011 and found it extremely helpful. The course materials were excellent and I enjoyed taking

part in the discussions which helped me to make connections.

I felt more able to take control of my life and learned how to make informed decisions about medication and alternative treatments. I was able to reduce my medication and I believe that the course was actually the key I needed to kick start my journey onto the right path.

There's a close link between physical and mental health and I now have the tools to manage both my conditions and the confidence to know when to ask for help.

It's eleven years since my last manic episode and I have a lot to thank Bipolar Scotland for and feel grateful for the opportunity I have as a volunteer to support them.



**Michelle Howieson**



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