Networking for Change

Event Summary
27th April 2017, Glasgow

Contents

Aims of the event

The aims of the most recent Self Management Network Scotland networking event, held in Glasgow on Thursday 27th April 2017, were to work together to answer the following questions:

- How do we effectively share knowledge within the Self Management Network Scotland?
- How do we use the knowledge within the Self Management Network Scotland to make change happen?

To answer these questions, attendees at the event were invited to provide a five-minute update on their work and their experience of networking and sharing the message about self management. In smaller groups, attendees then participated in two workshops exploring their ideas around networking and how they tell people about self management. The final session of the day focussed on specifying actions. Each attendee was asked to list at least one action they would complete after the event and their ideas for actions the Self Management Network Scotland team should complete.

On the day

A total of 91 people registered and, on the day, 66 people attended the event.

It was announced that the Self Management Network Scotland now has 500 members and attendees were shown a video that details the achievements of the network to date.

13 people were interested in delivering a 5-minute update. 11 people delivered an update at the event.

There were detailed discussions about how to describe self management in the Exploring Self Management workshop and several different definitions produced.

Blythe Robertson, Healthcare Quality and Improvement at the Scottish Government, assisted with the delivery of the Networking for Change workshop and shared information with attendees about the refresh of the Health Literacy Action Plan.

46 attendees specified an action they will carry out following the event.

Self Management Network Scotland Members' Update

Please find a short summary of each of the 11 updates from members below.

Hilda Campbell

Change and Sustainability Facilitator, COPE Scotland

How can we make self management real for people who wouldn't usually identify with the term?

Hilda spoke about work COPE Scotland have been doing to help get the wider population thinking about self management. They decided to establish an anti-obesity campaign – 'happier in your skin' – which was coproduced with COPE's members, as all their work is. Their approach has been to work in partnership with other organisations, helping to raise their awareness about ways of making their services and support inclusive and accessible to all people. Hilda gave a couple of examples such as helping a local yoga group purchase bolster cushions so that more people could attend their classes.

Adult Dyslexia Worker (self-employed)

Shared details of work with Dyslexia Scotland. Has helped to set up a support group for people with dyslexia to encourage peer support and mutual learning. Also develops self-help resources for dyslexic adults such as a list of resources for people to self manage with dyslexia and mental health conditions. Has also been involved in delivering workshops to help adults with dyslexia unlock the potential of books as self-management tools. Produced several book lists which have been published on the Self Management Network Scotland blog.

Yennie van Oostende

Health Improvement Specialist (Self Management and Long Term Conditions), NHS Highland – Argyll and Bute

Yennie described some work taking place within Argyll and Bute to improve the provision of services for people living with chronic pain. Having identified that pain services were patchy across the region, and mainly available in Oban, the Pain Toolkit was identified as a way of improving self management support for people living with chronic pain. They trained 26 physiotherapists and 9 health workers to deliver one to one support based on the pain toolkit. They also trained self management coaches, in partnership with Arthritis Care, to deliver three hour workshops for people. The NHS are the main referral route. They have found the Pain Toolkit has been a good way for people to engage with self management as a concept. They have received more funding through the Integrated Care Fund which will be used to train more health workers. Feedback has been that people no longer

feel so alone; and that it's not weak to admit having a long term condition - "I have a new normal which is my normal."

Deborah Slater

Voices Scotland Trainer, Chest, Heart and Stroke Scotland

Described the work of Chest Heart and Stroke Scotland (CHSS) to help health professionals make the fundamental shift in approach and mindset to become self management supporting. They also deliver support for people living with long term conditions around using their voice to influence policy and become a self management champion. They have learned that the courses they deliver help people recognise themselves as having skills and hopes. CHSS also provide an advice line staffed by nurses, peer support groups across Scotland and website support such as My Lungs, My Life.

Elaine Fitzpatrick

Project Manager and Facilitator, Realize Your Potential

Elaine is a young carers support worker and is currently delivering a self management project for young carers – using a course called QuEST. QuEST is about inspiring, supporting and enabling young carers to realise their potential. The project has been rolled out over six months – working with young carers to identify where they currently feel they are at, what skills and talents they have, where they want to get to, and then help them to overcome any challenges. Young adult carers are now delivering some activities in Dumfries who went through the course. Elaine also described a lovely story from a book she read – emphasising the point that if you get yourself ok then the world will be too.

Chris Myles

Addictions, Education and Prevention Specialist, NHS Ayrshire and Arran

Described work taking place across NHS Ayrshire and Arran to support self management. Within Ayrshire and Arran there are self management programmes available to people such as Moving On Together, WRAP, and Self Management and Recovery Training. They deliver these to mixed groups of people and the courses are delivered by clinicians and lay facilitators. In East Ayrshire, they are supporting people to deliver the Moving On Together courses by supporting their facilitators. In South Ayrshire, they are delivering lots of WRAP and Moving on Together in partnership with community mental health teams. They are also developing a self management handbook to help with detox.

Susan Kelso

National Allied Health Professions Lead Early Intervention, Scottish Government

Susan is an Allied Health Professional working within Scottish Government on the development of a new improvement programme for Allied Health Professionals (AHPs). The aim is to increase access to AHPs for people using health and social care support. Having carried out some consultations to inform the improvement programme they heard that many people did not know who AHPs were, how to get hold of them, and often felt they needed to see them earlier.

AHPs include healthcare professionals such as occupational therapists, physiotherapists, radiographers, dieticians amongst others. A focus on supporting people to self manage through helping them identify and achieve their personal outcomes for health and wellbeing is at the heart of the improvement programme. There are specific work streams around living well with dementia, children and young people, falls and getting back into work. They are currently carrying out a survey gathering feedback from people about where they are currently on their life course which they will use to gain a better understanding of how AHPs can work better with people.

Hong Zhang

Development Officer in Health and Social Care, Perth and Kinross Association of Voluntary Service (PKAVS)

Described the work they are coordinating through the third sector Perth and Kinross Health and Social Care Strategy Forum to help highlight the role of the third sector in health and social care integration. The forum meets every four to six weeks and now has over 100 third sector members. Self management has been identified as an area where the third sector has a leadership role. They will be taking forward some work to raise awareness of self management and the role of the third sector. The learning from a joint event with the Self Management Network Scotland has been fed back to the Partnership for future strategy planning.

They are also currently involved in developing a service model of pain management and one hoped for outcome is collaborative working to improve the pain pathway.

Michelle Howieson

Lothian Bipolar Group Facilitator, Bipolar Scotland

Described her work with Bipolar Scotland to help raise awareness of living with bipolar and ways to self manage. They offer self management courses and are piloting one for carers. There are 13 support groups across Scotland which offer peer support. Michelle facilitates the Lothian group. Members share tips such as for helping with sleep, and produce a newsletter every month which gets widely shared throughout Lothian. They have good partnerships with Lothian Recovery Network

and Advocav. They facilitate secret Facebook groups that help support people where their condition is not widely known. This includes a group for 18-30 year olds who can gain from networking with peers of a similar age.

Izabela Mertowska-Shand

Take Control Development Officer, Arthritis Care Scotland Young People and Families Service

Updated people on the work of Arthritis Care for young people. They offer Take Control course for 10-18 year olds and Joint Potential for 18-25 year olds. They are currently based in the rheumatology clinics of Glasgow, Fife and Aberdeen helping to reach young people who are newly diagnosed.

Izabela discussed some challenges encountered with networking and linking with health colleagues, as they work very differently to Arthritis Care Scotland. Networking within the third and voluntary sector feels like the dialogue is much more open. Izabela attended today to find out more about identifying positive opportunities for networking and joint working.

Stephanie Fraser

Chief Executive, Bobath Scotland

Spoke about Bobath Scotland's Teen Academy to help support young people transitioning into adulthood. Stephanie explained that cerebral palsy isn't seen like other neurological conditions and there aren't many specialist services provided by the NHS. Self management is key for people living with cerebral palsy and helping young people prepare for adulthood was identified as an important area of support for the people Bobath works with. The support had to be delivered at a time when the young people were not at school or other education and had to be tailored to what each young person wanted to achieve. They planned the sessions around their personal goals. They young people also shared that they wanted to work on being independent, share tips and techniques with others with similar lived experience and meet people experiencing similar challenges.

Graffiti Wall

During break times, attendees were asked to:

- Tell us about your experience of the Self Management Network Scotland
- Tell us about your hopes for the future of the Self Management Network Scotland

By adding their thoughts to a "Graffiti Wall". Please find some highlights of attendees' thoughts below.

Experience of the Self Management Network Scotland

"Excellent opportunities for networking and learning from others."

"Very interesting to hear about all the self management projects going on around the country!"

"Writing a blog on last year's Self Management Awards which were inspiring. "

"Writing a blog about taking personal supported positive risks to improve your life and move on."

Hopes for the future of the Self Management Network Scotland

"Local libraries as self management hubs."

"To be able to learn what would help carers of dementia regarding self management from all this great work."

"Networking events in many different localities."

"More service users' experience and more events like this future to keep up to date."

Workshop: Exploring Self Management

Summary

One of the aims of this event was to explore how the collective knowledge of members of the Self Management Network Scotland can be used to make change happen. For change to take place, we need more people to understand and talk about self management. It needs to become the norm for the delivery of health and social care services. Success will look like a partnership approach being taken across health and social care where people living with long term conditions, and unpaid carers, are equal and active partners in their own health.

In the Exploring Self Management workshop, attendees were asked to consider:

- What is self management to you?
- What ways have you used to talk about and describe self management and what helps people to understand?
- How can we spread the message of self management?

What is self management to you?

Attendees were shown some definitions of self management we have gathered before and asked to write their own. 42 different definitions were gathered emphasising that self management can mean different things to different people. However, many featured the same themes including:

- Being an expert in your own condition
- Partnership working
- Developing knowledge, skills and tools to manage long term conditions
- Feeling confident and in control
- Feeling like the support is there when needed
- Living life to the full
- Being supported to make informed choices
- Being active and not passive

A selection of the definitions describe self management as:

> "Working in partnership with health professionals to help me to improve my knowledge of opportunities and skills that will help me to improve my self care that I can implement to improve my quality of life to better live with and cope with multiple long term conditions and getting the most out of my life."

> "Working together as partners with healthcare professionals and others to help manage my conditions and understand what works for me and matters to me. Not one size fits all."

> "Being able to live a valued life with the support of the community around you."

> "It's about helping yourself lead the life you want to lead in collaboration with others."

> "Taking control, being self aware and in control of my condition with support. Building a support network: knowledge, services, family, friends, adaptations, health team. Plan and prepare for setbacks."

> "Getting health and support to be able to do the things you need or want to do in your life."

> "Having the tools to live one's life the way one wishes."

What ways have you used to talk about and describe self management and what helps people to understand?

Acknowledging that self management can be a difficult concept to express, we encouraged attendees to share their experience and knowledge with us and with one

another. In a discussion about how to describe self management and help people understand what is meant by this, attendees shared examples and tips.

- There needs to be an equal relationship between people and professionals where it is possible to have an open conversation. It is a two-way dialogue and sometimes the professional can have something to learn.
- Acknowledging and using people's strengths and them feeling confident in their own knowledge and experience. A positive focus on a person's strengths when delivering information is especially important at the point of diagnosis.
- It can be helpful to use comparisons to how life was before and how life is now. Or describe the opposite of self management.
- Other analogies people have used include workplace coaching and self management as a backpack "full of things you need that are always behind you."
- Many people spoke about the power of personal experience and of sharing stories about what self management looks like.
- Describing self management as different for everyone and having open discussions about alternatives and "life skills" people can learn and use.
- We need to normalise the term and talk about everyone self managing.
- Letting people know there is something they can do themselves and feel a sense of ownership is simple and effective.
- Practical steps like providing information on local services and support can be helpful.
- One attendee shared experience of working with young people, but this could be helpful for everyone:
  o Where are you at in your life?
  o What skills and talents do you have?
  o What do you want to do?
  o How can you get there?
  o Explore ways to overcome challenges.
  o Introduce the concept of self management.

How can we spread the message of self management?

There were many suggestions for ways to spread the message of self management. A selection of ideas is listed below.

- Ambassadors can share stories and their experiences of self management. Peer to peer interactions can be helpful or using someone well known to tell their story.
- Young people are great promoters of what works for them.
- Going beyond talking about self management and changing both the language and the approach to create an equal relationship between professional and person in the role of patient.
- Create resources that can be downloaded sharing information about self management.
- Involvement of academia and speaking to students.
- "Pay it forward" style challenge to encourage people to share their stories and do something to help someone else self manage or understand the concept.

Outcomes

1. We gathered a wide variety of up to date definitions of self management which cover many different areas of experience.
2. We discussed how to spread the message of self management to people with others who have done this successfully. Ideas can be utilised in future Self Management Network Scotland activities.

Workshop: Networking for Change

Summary

The second aim of this event was to explore how the 500 members of the Self Management Network Scotland can communicate effectively with one another. It has always been an important aspect of our work for the network team to be led by communication activities that members already use and already find effective.

Attendees were asked to consider:

- How do you currently share information within your networks?
- Do you have any ideas of information sharing activities we could use across the Self Management Network Scotland?
- Choose one of your ideas and work out what it would look like in practice, considering:
   o How you would describe your idea.
   o What does your idea need to get started?
   o Who needs to be involved?
   o How will you know it is working?

Brainstorming

Attendees were asked to brainstorm ideas for information sharing and networking activities. These could be new ideas or activities they have experience of. Ideas included:

- Presentations at team meetings
- Library services network
- Find a local network champion
- Accreditation of organisations to enable them to contact people outside of their area
- Local self management network meetings
- Patient group
- Identify missing sectors, e.g. education
- Social media

Work it out

Following the brainstorming session, attendees were asked to select one of their ideas and "work it out." Working as an individual or in groups, attendees thought through what their networking idea would look like in practice and considered what and who would be required to get their idea started.

Describe your idea	What does it need to get started?	Who needs to be involved?	How will you know it is working?
Champions model: could be condition specific or other topics/ areas			
Having champions for sub-groups of interest) specialist focus) i.e. health literacy.	Identify common areas of focus. Clear expectations of what we need person to do (role description for a champion). Find people who are passionate. Strategic agreement between Alliance.	The Alliance communications team. Management agreement from other organisations. Champion. Learning and development team at the Alliance.	Champions in place. People understand what champions do. More networking and shared learning. Shared understanding and skills.
"Accreditation" (not licensing, may not be correct term- it is a quality mark)			
Small/ locally based organisations but with 'national' interest- condition specific remit have difficulties networking/ influencing outside of their immediate geographical area- can we credit or legitimise representatives? E.g. Peer groups so they are credible when approaching some (mainly statutory) services. i.e. they are recognised as legitimate so they can gain access. Like a "kite mark"- who would provide this accreditation?	How do you regulate this? Organisations need to demonstrate they fulfil specific criteria and sign up to a code of conduct. Evidence of self management role and work. Information provided. Trusted mark. Need criteria, submission, e.g. evidence and training.	Steering group	Feedback loop

Describe your idea	What does it need to get started?	Who needs to be involved?	How will you know it is working?
List of attendees			
List of attendees at Self Management Network Scotland meetings and local meetings. Makes it easier for networking. Identify local area or national.	Email out list prior to meetings including area of interest.	Alliance. Organiser of meeting.	Self evident

Outcomes

1. The idea of 'champions' within the Self Management Network Scotland was popular and we will develop a plan for this.
2. Explore possibilities of providing some sort of "accreditation" for smaller organisations. (This will not be in the form of a rubber stamp from the Health and Social Care Alliance Scotland but we will work to develop ways to forge and strengthen links between local community organisations and statutory services.)
3. At future events, people registering will have the opportunity to give their consent for their contact details to be shared with other attendees.
4. Many of the ideas generated in this workshop were activities for promoting the network and finding new members. We will explore these opportunities as we continue to grow the Self Management Network Scotland.

List of Actions

In the final session of the day, attendees were asked to list at least one action they will carry out following the event and to list any actions they thought the Self Management Network Scotland team should carry out.

Attendees will receive an email reminding them of their action two weeks after the event and a follow up email in eight weeks to find out about their progress. The full list of suggested activities for the network team is below. We will be working through this list to carry out the actions suggested. Look out for further communications from the Self Management Network Scotland and on our blog to track our progress.

- Provide us with a list of attendees today and email addresses, where appropriate.
- More a mix of participants. A lot of the table were charity employees, health professionals and health employees service. More of a mix- should be actual

patients who do more to challenge the system and not opposed to keeping the norm. Questioning. This then opens discussions.

- Keep network updated with new ideas and concepts.
- Find a way of creating an online forum for sharing ideas between Self Management Network Scotland events- not everybody is here- how to involve whole network.
- Keep in contact regarding sharing good practice and ideas that are working for us. Narrow down SM into smaller headings/ topics so we don't get overwhelmed with too much info and that is maybe not so relevant to own project etc.
- Please compile a list of people who are registered to attend your national events like today and include it in the welcome packs. Give each person's name and their affiliation/ role.
- List of members with interests or project ideas (sight related preferable).
- Share information and actions that are developed as a result of today's event.
- Would be good to have a delegate list with synopsis of people's roles, experience to help with networking in future.
- To keep in touch and keep us informed especially about developmental activity around local network leads.
- Explore opportunities for strengthening links with AHP active and independent living improvement programme (AILIP) to change mind-sets towards self management and look to spread existing good practice.
- Improve sharing best practice through story telling.
- Slack. For future events looks at swap card.
- On name badges put the name of the group the person works with
- Support development of toolkit to support better conversations about self management.
- Regularly being in touch to exchange ideas and share learning.
- Keep in touch with groups.
- Help me identify/meet similar self management network people across Scotland that I can work with on developing House of Care spread and become the norm.
- Continue contract work. Raise profile? Celeb endorsement/ sponsored ad.
- Is there a list of all members/ organisations split into working areas or localities that can act as a directory for organisations to work together?
- More evidence/ examples of the five principles and how effective they are to supporting self management.
- Update website. Bullet list points of the day (today). List of participants and who/ what they represent and email.
- To share information from today's event.
- Look into themed/ interest based email list of attendees/ members of Alliance.
- Facilitating face-to-face huddles service users talking to service providers and commissioners.
- Signpost to good training examples nationwide on self management for specific groups, carers, professionals and service users so we can find easily courses specific to conditions and people facing those issues.
- To provide information about the other members to each of us so that we can develop more links.
- Find a way to make networking easier accessible.

- Seek way to develop accreditation- accreditation steering group to seek way to implement.
- Share what was said in other groups.
- Organise more of these events regionally. Build connections with education department to formalise.
- I would find it helpful to receive an email with the feedback/ comments/ actions from today.
- Add me to the members list! I want to join the network!
- Work with schools and colleges and nurseries to promote self management as it applies to life regardless of health issues or conditions
- None
- Forward summary that I can circulate to newly forming Edinburgh network.
- More meetings like that.
- Follow up from today's suggestions/ ideas.
- Populate membership of website.
- Thinking of ways for network members to find each other- promote the collaboration angle- today has been hugely helpful for this but how can we do this out with such events. Could we have regular conversation cafes?
- Advise how I can effectively link in with Links Worker, etc.
- Circulate delegate list. Populate network website with profile of members. Advocate libraries to all members of the Alliance!

Evaluation of event

43 evaluation forms were submitted from the total of 66 attendees. If you did not complete an evaluation form, you can download one from our website and return to smns@alliance-scotland.org.uk

How would you rate today's event overall?

Excellent	18	(41.86%)
Very good	15	(34.88%)
Good	09	(20.93%)
Disappointing	00	(00.00%)
Very disappointing	00	(00.00%)
No answer	01	(02.33%)

Do you think you have had a chance to discuss your ideas about effective networking and hear about other people's ideas?

Yes	41	(95.35%)

No	01	(02.33%)
No answer	01	(02.33%)

Do you think you have had a chance to discuss your ideas about spreading the message of self management and hear other people's ideas?

Yes	41	(95.35%)
No	01	(02.33%)
No answer	01	(02.33%)

Is there something today you found particularly useful? For example, have you met someone new, learned something new or had an interesting discussion?

Met someone new	19	(44.19%)
Had an interesting discussion	11	(25.58%)
Learned something new	09	(20.93%)
Not answered	04	(09.3%)

"Really enjoyed start of the day hearing from a variety of others"

"Good networking opportunities"

"It was interesting to hear about the differing implications of the term 'self management' in different contexts"

"How to explain what self management is to other people. Tended to use jargon but need simple, real life words to use."

Is there something you would change about today or something you think could have been done better?

Catering	01	(02.33%)
Venue	01	(02.33%)
More breaks	02	(04.65%)
Better mix of people and roles	02	(04.65%)
Workshops could be improved	02	(04.65%)
Mix up groups of people	03	(06.98%)
Timing of the day	03	(06.98%)

Send list of attendees   06   (13.95%)

No   06   (13.95%)

Not answered   17   (39.53%)

"More individuals with long term conditions"

"More time for hearing good practice, looking at next stages for Self Management Network Scotland and current work."

"I would have preferred to be in a different group/ room for afternoon breakout to meet and network with more people."

"The idea of an attendee list was something I think would be useful."

Do you have any other comments?

"Congratulations on a very well-paced event, found you all very personable and passionate about the subject."

"Thank you- loved the venue!"

"A lovely day with like-minded people and all positive about working with the library."

"Great venue. Would have been good to have everyone introduce themselves."

"Good event, useful, enjoyable and a good day."

"Well organised event- lots of enthusiasm."

What next?

- You have been sent a note of the action you detailed for the day and we will be in contact again in eight weeks when it will be great to hear about your progress. (If you didn't receive a note of your action, we either did not collect a worksheet from you or you did not include your name. You can download an action worksheet from our website and return to Self Management Network Scotland@alliance-scotland.org.uk)

- The Self Management Network Scotland team have a development day planned in May 2017 where we will discuss your suggested actions and

networking activities. Look out for future Self Management Network Scotland updates where you can track our progress and find out about future events.

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Scottish Government

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