Living Well Engagement Report

What We Did

In order to access the lived experience and understanding of people living with long-term conditions, we held three sessions to discuss the strategy and what people's priorities would be.

Region	Group	Date	Session Type
Mid-Argyll	Lochgilphead MS Centre "Brain Fog Friends"	28th Jan, 2019	Focus group
Kintyre	Campbeltown Link Club	7th Mar, 2019	Focus group
Islay & Jura	ChitChat Islay – Activity Showcase	15th Mar, 2019	Open stall

Each session built on the previous sessions, and was designed to meet the needs of the group involved. The aim was to have an open discussion, led by the participants, which would allow people to highlight key needs, gaps, and priorities which staff and working groups might not have considered.

We have also developed two surveys which will be sent out in April to bolster the results by broadening the capacity of staff and community members to engage with this process. The first survey (Appendix 1) is aimed at service users with long-term conditions and their carers, and asks similar questions to those raised in the focus group and discussion sessions, while the second survey (Appendix 2) is aimed at staff and asks them to assess their capacity to support people in self-management, as well as how this capacity can be extended.

Individual reports have been prepared on each of the sessions above. This report aims to synthesise the results of these discussions and highlight emerging themes and priorities. We approached the discussions along the lines of four categories of question, but it is important to note that these interplay with one another and have mostly been separated thus for ease of understanding.

Category 1 – What Keeps Us Well? How Do We Self-Manage?

In Lochgilphead, we asked people how they kept well, and who they involved in this process. Carrying this forwards to Campbeltown helped to build up a model that included both physical and mental long-term conditions. In Islay, we asked participants to write down their answers to "What keeps me well?" and "What can **I** do to self-manage my condition?" Between the three sessions, the following themes arose:

Community Support
People credited being part of a community or support group with keeping their health up. It was important to be heard, believed, and respected by the people around them. Having a support group may give people a reason to get out of the house, and may also help the symptoms of a flare-up to be noticed sooner.

Exercise and Diet
Exercise may be difficult or intimidating for some people, but can help people to maintain tone and strength, to socialise, and to improve their mood. Diet is also important, and can be a useful, measurable thing to manage to help improve symptoms.

Mindfulness and Meditation
For both physical and mental health, frequent mindfulness, meditation, and gentle activities like Tai Chi were highlighted as being helpful in self-management. Courses offered in these things by the MS Centre and Kintyre Link Club were mentioned as supporting.

Distractions and Activities
People said they felt best when they felt that they were "useful" and "needed", and that having available, accessible activities helped them to self-manage. This could be walking the dog or gardening, or craft clubs like those offered in many support groups. Volunteering was mentioned as particularly good, as it allowed people to feel they were being helpful.

Medication and Medicine
Medication is an important part of many people's self-management process. This medication may be pharmacological (for example, painkillers or antidepressants) but it may also be a more holistic approach: acupuncture, oxygen therapy, and massage were all mentioned as important medical interventions for people.

Information and Signposting
Access to information about one's condition and treatments alleviates anxiety and helps people to feel more independent and autonomous. It is also important to be able to access information about services that are available both locally and nationally.

Emotional Support and Respect
A recurring theme was the need for people to feel that their emotional and mental health was being upheld, whether their condition is physical or mental. This may mean formal mental health care provision, or may involve friends and family being informed about emotional needs. It is also vital for people to feel heard, respected, and understood by others; education of others was highlighted as being very helpful to this.

"Be Kind To Yourself"
An important theme arising was the need to be gentle with oneself in self-management processes, not pushing oneself too hard or feeling that targets need to be met. Rest, relaxation, and warmth/comfort are key to self-management, and people mentioned how important it was to have this be an ongoing process of self-forgiveness.

Sharing Stories and Experiences
This helps both in terms of emotional support (sharing stories makes people feel less alone and isolated, and helps to build mutual understanding) and practical self-management (people can share their experience of what has and has not worked for them). It can also support signposting and building community.

Category 2 – What Services Are Available? How Do We Find Them?

Several specific services were mentioned in our focus sessions, primarily volunteer and community groups like the MS Centre, Link Groups, the Dochas Centre, and Chit-Chat Islay. Other kinds of services which were mentioned were:

- **Pain clinics**, although these were rarely local and may require travel
- **Walk With Ease** and **Pain Toolkit** courses
- **Physiotherapy**
- **Pharmacists** could help with providing medication and advising on self-management
- **Online support groups**, whether on Facebook or other forums. However, people found that some groups suited them better than others, and it wasn't always easy to identify the best groups.
- **Advocacy services**

We asked how people found out what was available. Answers included:

Online
People often found support either through Google searches for their condition, or through social media. However, very few people were aware of NHS Inform or similar NHS websites.

Word of Mouth
People often identified services after being told about them by friends, family, or other people in their support groups.

Community Postings
This could be posters or leaflets in public spaces, or it could be through articles in the media, discussions on local radio, etc. Many people had discovered services through notices posted in doctor's surgeries, pharmacies, or community centres.

Referrals
The frequency of referrals to non-HSCP services seemed to vary a lot between groups. However, some people said that they had been referred to local services or courses by HSCP front-line staff, particularly identifying OTs, GPs, and psychiatrists as common referees.

Support Groups and Advocacy Networks
People also found out about services through their support groups, and through interactions with the Lomond and Argyll Advocacy Service (LAAS)

Category 3 – What's Missing? Where Are the Gaps?

We asked participants in all sessions to identify the gaps in support, although the phrasing varied somewhat: in Lochgilphead and Campbeltown, we asked "Where are the gaps in services and facilities? What's missing to help you self-manage?", while in Islay the question was "What do I need?"

Themes that came out of this discussion included:

Continuity of Care
There is a perceived lack of continuity both within and between services, with information being lost in the process. The setup of some GP practices can make it difficult to ensure people can see the same doctor, which would let them build up a relationship and understanding.

Transport and Accessibility
Many courses and specialist clinics are not available in the area, or require a long journey to attend. This can prevent people from accessing services. It was suggested that VC/teleconference consultations, improved transport services, and/or more local visits could help more people to access support. Flexibility in appointments could also be useful.

Accessing Information
People often struggled to find information about their conditions or what was available to help them. There is a lot of information, which may be difficult to process, and much of it is irrelevant or out of date. Most information is online, which may not be easy for everyone to access.

Professional Input and Understanding
Several people felt that it was difficult to know who to turn to or how to access professional help. It was noted that many health professionals were unaware of local services and support, and that it could be difficult to communicate without knowing the "right words".

Holistic Approach to LTCs
It was highlighted that often different aspects of illness (e.g. physical and mental symptoms, or long-term conditions and their impact on acute health) were taken entirely separately, and that a holistic approach was needed to tie together symptoms and treatment. A holistic approach is also needed in finding the balance between HSCP services, third sector services, and community services; these groups do not always work together as closely as they might, or share all their information.

Public Understanding
Many people struggle with stigma around disability and long-term illness, and with taking the first steps into seeking support. Public understanding is needed to support people at diagnosis, as well as to make it easier for people with LTCs to find supportive relationships among friends and family.

Space for Sharing
A comment received more than once was that these sessions were valuable because they provided a space for people to talk about their experiences, share stories, and find community in their experiences. This space does not always exist in day-to-day life. It would be helpful to connect people with and without long-term health conditions, across Argyll & Bute, to share stories and compare experiences. This would also improve public understanding.

Category 4 – What Should We Prioritise?

At the Lochgilphead and Campbeltown sessions, people were asked to contribute their own priorities which they would like to see included in the Self-Management Strategy process. The following themes arose:

- **Better information availability and promotion of services**.

- **Workforce development**. Specific focuses for this include:

    o engagement with LTCs

    o education on self-management

    o improving knowledge of available services

    o improving language used

    o prioritising outreach around services.

- **Continuity of care**.

- **Local access to support.**

- Providing avenues to **share people's stories and experiences** more widely. **Recognising** and **believing experiences**

- Need to cover "**physical, mental, and social" support**. A **holistic** approach.

At the Islay event, these and other considerations were synthesised into a list of suggested priorities, which people were invited to vote on:

Developing case studies/films and sharing the stories and lived experiences of people with long-term conditions	●●	2 (7%)
Clarifying the processes people can go through to access support at the right time, clarity on who can refer to when and when people can self-refer, and how they do that for all services (both statutory and community)	●●●●●●●	7 (24%)
Look at how we can better support continuity of care, including the use of personal self-management plans.	●●●●	4 (14%)
Improving access to information on managing long-term conditions, promoting where to find good quality information.	●●●	3 (10%)
Improving access to support including signposting to community support, peer support, and helpful services.	●●●●●●●	7 (24%)
Enabling healthcare professionals to engage in a more person-centred, holistic approach, including increasing their understanding of long-term conditions and their impact on people's lives.	●●●●●●	6 (21%)

The top priorities appear to be:

Clear processes and access to information.

Improved signposting and referral.

Holistic approach and professional understanding of long-term conditions.

Continuity of care.

People were also asked to contribute words that they associate with self-management, to help us with our strategic development and branding. These words, along with those decided by the working group, are below:

planning
together
education
reflect
be you
belief
empower
re-regulation
in the driving seat
take charge
confidence
adaptable
recognition
wellness
in control
energise
engage

Appendices

APPENDIX 1 – Community Survey

APPENDIX 2 – Staff Survey

APPENDIX 3 – Individual Reports

Lochgilphead report.docx   Campbeltown report.docx   Islay report.docx