

Pilotlight Living Well

Focus group feedback 8/12/16



Method

An evaluation focus group was run as first step in a process of an external evaluation by VIE.

The evaluation focus group was run as a 2-hour session at the end of workshop 8. The focus group covered:

1. Experience of the Pilotlight co-design process
2. Outcomes resulting from the project so far
3. Anticipated or desired outcomes from the implementation phase of the project

Jenni Inglis, VIE's Managing Director, led the focus group. IRISS staff left during the session on the experience of the process and Josie Vallely re-joined to assist with capturing feedback about outcomes.

Jenni introduced herself to the group, explained her remit, and gave each group member a consent form for their participation, which everyone signed prior to commencing the focus group.

Three of the group were unable to stay/attend so Jenni followed up with a phone call and has included their feedback in this report.

Future evaluation activities will consider the effect of the implementation phase of the project.

1. Feedback on the Pilotlight Living Well process

Participants were given a process map to remind them of what the project had included. They were asked to mark how they felt about each point on the process individually and note any stand-out moments.

Ten sheets were returned and these have been aggregated for this report. An overview of the process and some representative responses are shown on the next two pages, figure 1.

All participants gave very positive feedback about the facilitation approach, e.g.:

“Excellent job carried out by facilitators throughout the 9 months, thanks.”

“Facilitators were polite and made attending a pleasure.”

“Considerate facilitation throughout.”

“Everyone had equal time to speak.”

“Well presented and organised workshops fostered a rapport with all participants.”

“Kate and Judith were very welcoming and were able to explain the concept very well and that meant we were able to engage.”

“Mixing the groups up was really good, so you met everyone.”

“I was quite vocal if I had questions and sometimes wasn't sure if I was on the point but nobody made you feel silly.”

“Judith and Josie put so much effort in to make it positive and enjoyable.”

“The 8 weeks may have seemed a great commitment but it was worth the time.”

The fact that people who use services and carers were paid for their participation attracted positive comment:

“What was good, (was that) people and carers were paid and that guaranteed their presence for every meeting.”

Several participants commented that they would have liked more people who use services and carers to participate:

Would benefit from clients/ carer more involved, even if not able to make 8 sessions, there could be other opportunities.

However one person felt that too much attention was paid to trying to attract more people who use services and carers:

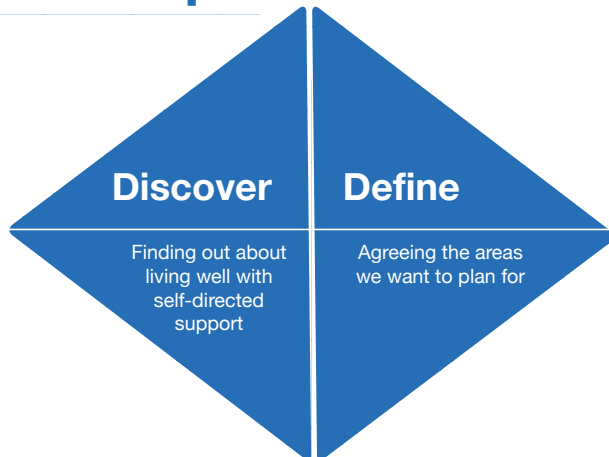
“The thing we got stuck with as a group, getting more people involved. It was less of a response than they (IRISS) were expecting.”

Process Map

Before

Information and awareness sessions

Sign up to Pilotlight



Workshop 1 10th March

- Getting to know one another
- Finding out about Pilotlight and co-design
- Thinking about how we want to work together
- Learning about self-directed support – values and principles
- Action Research

Workshop 2 7th April

- Recap on Workshop 1
- Signing off our Working Together Agreement
- Learning more about self-directed support and the 4 options
- South Ayrshire Market Place - local supports
- Research Analysis
- Barriers and opportunities self-directed support offers for Living Well

Workshop 3 9th June

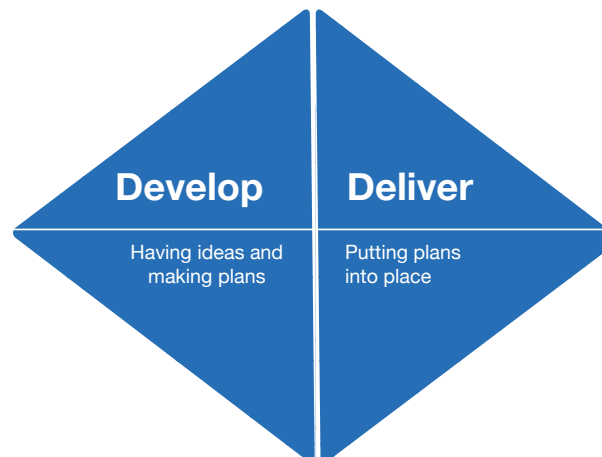
- Recap on Workshops 1 and 2
- Developing our Pilotlight Characters
- Designing journeys for our Pilotlight Characters
- Hearing some self-directed support stories from Ayrshire Independent Living Network
- Discussing and agreeing the themes emerging from our research

Workshop 4 21st July

- Recap on Workshop 3
- Thinking about what good information looks like
- Starting work on our theme 1 : Information
- Starting work on our theme 2 : Clear pathway
- Hearing some more self-directed support stories

Develop

Having ideas and making plans



Workshop 5 18th August

- Recap on Workshop 4
- Starting to develop our South Ayrshire Community Asset map
- Continuing work on our theme 1 : Information
- Hearing about the South Ayrshire Health and Social Care Partnership's Dementia Review
- Continuing working on our theme 2 : Clear pathway

Workshop 6 15th September

- Recap on Workshop 5
- Reviewing our South Ayrshire Community Asset Map and webpage and agreeing next steps
- Reviewing our Post Diagnostic Support work and agreeing next steps
- Starting work on our theme 3 : Bespoke Support
- Hearing about new developments with carers and self-directed support
- Starting work on our theme 4 : Support for Carers

Deliver

Putting plans into place

Workshop 7 20th October

- Recap on Workshop 6
- Refining our post diagnostic support work, Dementia Toolkit and webpage
- Continuing work on our theme 3 : Bespoke Support
- Hearing more about support for carers in South Ayrshire
- Continuing work on our theme 4 : Support for Carers
- Planning for our final workshop on 8th December

Workshop 8 8th December

- Recap on Living Well workshops
- Signing off our post diagnostic support letters, Dementia Toolkit and webpage
- Hearing about the development of Ayrshire Life
- Reviewing our SDS for CPNs Learning and Development Design Brief
- Reviewing our Carer Support Planning Toolkit
- Voting on names for our Toolkits
- Christmas Lunch and Secret Santa
- Evaluation Focus Group

LIVING WELL



After

Before	Discover	Define	Develop	Deliver
<p>Only a few participants commented on their experience before the workshops started. It was generally positive:</p> <p>“Engaged, included, aware of what I was going to be part of and excited to get started.”</p> <p>“I was glad to have met the facilitator before taking part. They were interested in me, and my role, and I knew what I was signing up to.”</p> <p>One person commented on a delay:</p> <p>“Awareness session was well delivered but there was a delay in the project commencing due to a change in partners who would be involved.”</p> <p>Another said it:</p> <p>“Felt like a lot of commitment to start.”</p>	<p>Workshops 1 and 2 were generally well received, e.g.:</p> <p>“Really enjoyed first workshop.”</p> <p>“Felt part of something very quickly.”</p> <p>“Well-presented and organised workshops fostered a rapport with all participants.”</p> <p>“Got to meet very nice people and spoke about their personal journey.”</p> <p>“Lots of care taken to make everyone feel comfortable and encourage participation.”</p> <p>There were, however, a few challenges:</p> <p>“Getting to know one another was good but other people came on board later and didn’t have an opportunity to introduce themselves.”</p> <p>“Starting from a clean slate was hard. It is hard to put your professional training to one side and start from what people are saying. Judith and Kate were good at not personalizing the issues.”</p> <p>“Slightly overwhelmed, lots of professionals and not many people with dementia or carers.”</p>	<p>Workshop 3 received only positive comments, e.g.:</p> <p>“Good conversations emerged from stories.”</p> <p>“Eye opening. Great to see examples of SDS used successfully.”</p> <p>“Feeling more comfortable and able to contribute.”</p> <p>“Enjoyed learning about SDS pick and mix, AILN and traffic light system.”</p> <p>Workshop 4 received more mixed reviews:</p> <p>“This workshop was fantastic. I felt that I learned a lot about the right way to present info. Helpful for my own project. Andy was great.”</p> <p>“Session 4 got hijacked by people with their own issues. SAC employees were not present. This was addressed at workshop 5 where both SAC employees presented information.”</p> <p>“Challenging part of the project, difficult to agree a focus going forward.”</p> <p>“More questions than answer at this stage. Facilitators stuck to their task.”</p>	<p>Workshops 5 and 6 were almost exclusively good experiences:</p> <p>“Both very good. I was able to find out more about what was happening in the community and be involved in making changes.”</p> <p>“At this stage the group had formed and was working well together. It was becoming clear what and how we would develop appropriate resources.”</p> <p>“All suggestions were always taken on board and changed things the group agreed on.”</p> <p>“Even if you missed a workshop – emailed information to read.”</p> <p>“Exciting to see ideas taking shape.”</p> <p>“Loved the map & sharing local information. Well organised.”</p> <p>Two participants thought there wasn’t quite enough time:</p> <p>“Question and answer not long enough.”</p> <p>“Group discussions could have been allocated more time.”</p> <p>Workshop 5 was harder for one participant because they didn’t have local knowledge.</p>	<p>Workshops 7 and 8 were very highly rated:</p> <p>“These two workshops were the high point of the project as we could see what we had achieved.”</p> <p>“Great workshop at the stage where I really enjoyed coming along. The prototypes developed are all great.”</p> <p>“The balance shifted from professionals in the early workshops to carers taking the lead, etc.”</p> <p>“Good quality discussion. Lack of time to fully explore ideas. Wide variety of activities keeps things interesting.”</p> <p>“Enjoyed lunch, Santa and the elf.”</p> <p>“Could have done 10 workshops.”</p> <p>“Tool kit is great.”</p> <p>“Great example of co-production at work.”</p> <p>“Activities were engaging.”</p> <p>“Excellent results from the workshops with new tools that can be introduced to help support people with dementia.”</p>

Figure 1- Experience of the Pilotlight Process

2. Feedback on outcomes (changes) achieved so far

Participants were asked to discuss the outcomes of the project on their tables. To aid the discussion the broad topic of “change” was broken down into three themes; reflecting aspects of the project that were likely to have affected people:

- What difference has working in a diverse team made to you?
- What difference has working with the creative tools made to you?
- What difference has exploring the issues and opportunities around SDS made to you?

Each table was provided with these questions, printed in large text, and were asked to discuss the question and write their answers on the sheet.

Overall feedback included being impressed with the results and learning about the early onset dementia, not just self-directed support:

“At the end of the day you actually came out with something! That’s unusual. I’m involved in a partnership and there’s never anything at the end of it. Like rearranging the deck chairs while the Titanic sinks.”

“That’s what I could say I got out of it- that not many people know about early onset dementia- it can be about character changes, impulsive behaviour lack of inhibition. Semantic dementia- learned about this, which I didn’t know. Really useful.”

Positive results of working in a **diverse team** included

- **Revisiting working practices:**

“I think at times you can rest on your laurels and then when you actually talk to them (people who use services and carers), it challenges you. It helped look at the quality of what we deliver”.

- **Practitioners knowing more about about each others' work:**

“Another good thing that Judith did was give all the professionals, including the third sector, a chance to talk about their services. That increases your knowledge and makes sure everyone gets a chance to feel equal.”

“Getting to know other people and build relationships, traditionally professionals would stick together. Telling people where to sit, encouraged more conversation and learning.”

- **Practitioners having greater understanding of people's real experiences:**

“Having people in the group that had dementia- then you can see the difference it makes to people and seeing how it affects families.”

“It was great to have people with early onset dementia there- so it brought it home the devastating impact on people, it can cause all sorts of issues, for example bullying.”

“It's made it more about people rather than a system.”

“Seeing from different perspectives made me more knowledgable”

- **People being more confident:**

“Given me confidence to talk to other people”

- **It also highlighted a gap in other initiatives and services, that they tend to work only with carers or only with the person cared for:**

“It's the only chance I've had to attend something with the person I care for.”

A few challenges of working in a **diverse team** were noted, but participants felt they had been dealt with adequately in the Pilotlight process:

“It was very challenging. I needed to stop being protective of my service.”

“The only thing, sometimes some of the groups went on too long. It depends what group you were in. People work at different speeds and you have to be fair to everyone.”

Positive results of using the **creative tools** included

- **Revisiting working practices:**

“I learned some new skills and some better ideas- e.g. using more brightly coloured things and art, I learned from it and we’re doing a team building event and I’ve put in some ideas and they’ve been incorporated. It makes you think outside the box.”

“I’ve done similar stuff before I don’t know why it worked better, I think it was the mixture of people and everyone entered it in the right spirit.”

“I’ve not done anything like this before, well nothing to such an extended period time. It was fun and enjoyable and I learnt a lot.”

- **Being able to apply to tools and/or benefiting from the use of the tools in the workshops:**

“Tools have helped me in personal life.”

“The tools were memorable, helped me to remember.”

“Seeing things, drawing and making things has given me an outlook on my life.”

“I understood all the activities.”

“Characters sketching created a good rapport.”

“The creative tools made me think more flexibly.”

Positive results of **exploring SDS** included

The tools that were developed:

“It’s made a difference because of the tools that have come out of it. We’ve incorporated that from January, we’re rolling it out. It’s a nicer letter, its not as clinical and more user friendly, the carers’ questionnaire will be used more.”

“It’s given us the carers’ assessment the new appointment letters and a dementia toolkit. It’s taken on board what carers and patients have said.”

“The carers’ questionnaire, it puts it in a format and part of a process, beforehand I asked person-centred questions sometimes but now it will be standardised across the whole team.”

“I thought the carers’ assessment tool was excellent and can see that being used.”

Improved understanding of SDS:

“Its made me understand about SDS a bit more. I can see that in certain instances it is good to have the money and to hire someone yourself. We have people who want to come and get support and sometimes it might have been helpful.”

“I already knew a fair bit about it but what it did do was explode some of the myths and it ties it all in together. Before, at times, there’s a thing where the patient is who I need to focus on, and the carer can get left behind. The team is more aware of Self-Directed Support. We’re trying to increase people’s awareness.”

“I realised that SDS is not appropriate for everyone, for some people it is wonderful giving choice and control but for others it means too much responsibility. This has been a learning curve.”

“I’ve become more interested in the national situation on SDS.”

Improved understanding of the health and social care system:

“I now know much more about health and social care teams and their roles.”

“I now have names to faces and important contacts.”

“I am now informed to be able to ask questions.”

However, not everyone felt **exploring SDS** had made any difference, nor even that it was the best focus for a co-production project:

“For me it wasn’t about the SDS I don’t see that can help very much, e.g. getting a wee bit of money every week.”

“I’m not sure whether we got everything we were trying to get from it, e.g. to sell SDS to carers. It is the way Scotland is going to go, so is there going to be a choice in the future.”

“SDS can be used by people with a political agenda to justify cuts, funding needs to be maintained”

Jenni has combined these comments with others to make a logic model showing what change participants said had happened as a result of the Pilotlight Living Well project, see figure 2.


Outcomes for participants	Participants are proud of the well-designed tools that result from the project.	Participants understand more of the potential for SDS	Improved understanding of the health and social care system and confidence to engage with it.	Practitioners are more aware of carers when working with people who use services.	Practitioners use and adapt these creative tools in other work enabling greater involvement.	Practitioners improve the quality of service delivered.
Initial changes for participants	Participants are able to speak freely and work productively together.	Participants learn from different examples of how SDS has been used	Participants explore the realities of people's experience of health and social care.	Practitioners hear more of the perspectives of people who use services and carers.	Practitioners learn about and practice using creative tools for involvement.	Practitioners learn about the effects of early onset dementia and perceptions of services.
Engagement			Most members of the team participate in most of the workshops	 <p>Direction of change</p>		
Activities			8 workshops following the double diamond process			
Inputs			Funding and in-kind support necessary to resource a co-design team			

Figure 2- Logic model showing change so far

3. Developing indicators of future success

Lastly participants were asked to thinking about their aspirations for what the project might achieve in time. They were asked to think about how project learning could be applied. Based on this what would success look like, what were there hopes for the results of the project. They were asked to capture these on another sheet.

Comments about hopes for the **future outcomes of the project** included

- **Great optimism about the potential for the tools to be applied and to improve people's experiences:**

“Fundamentally, you want the patient’s experience to be better and the service to better meet the person’s needs. There’s a target that there would be more people applying for SDS, you’d like it to be far better. And you hope that the dementia toolkit will give you positive feedback, you want to hear “see that folder, that gave us lots of information about Mrs. Jones or Mr. Smith.”

“Now feels like people are open to make a change.”

“Alzheimer’s Scotland are going to use the toolkit.”

“People involved in the project will work better with those with dementia.”

“People will feel empowered by the letter.” (to be sent post dementia support visit)

“Dementia toolkit structure will provide a clearer pathway.”

“Pathway will be clearer.”

“Training to CPNS and the people with a diagnosis who start their post diagnostic support will be better informed”

“More people in South Ayrshire being able to access the support that suits them.”

- **Two suggestions for how the tools could be further developed/ spread:**

“Can we promote this through surgeries, libraries, etc.”

“A small A5 toolkit would be beneficial.”

- **Some hopes for how the way the project has worked could be more widely adopted:**

“Policy made on the basis of practicalities rather than theory.”

“Encouraging a movement towards including people who use services.”

“Busting stereotypes.”

“Doing the work not talking the work.”

“Feeling able to go to people and confident to know who they are.”

“Move away from jargon.”

“More person centred/ focused on the person.”

“Effective communication and joint working.”


“Educating CPNs in SDS and flexibility to think outside the box.”

In most cases it is clear the implementation of the products of the work could lead to participants’ desired outcomes being fulfilled. However one of the participants had a hope for an outcome that does not appear to be addressed by the project:

“We need to get the message out that drinking is very damaging. We have a dreadful attitude to drinking. I hope that there’s more awareness for mental health issues and that there’s more awareness that being high and dancing on tables means they are actually quite sick.”

Jenni has combined these comments to make a logic model showing what change participants hope would happen as a result of the Pilotlight Living Well project in future, during the embedding phase- figure 3.

Outcomes	Other services and pathways are better designed to reflect the diverse experiences of people who use services and carers.	People with early onset dementia and their carers have a better experience of services and access services that better meet their needs.	CPN's work is more person-centred and carer aware and therefore achieves better outcomes.
Initial changes	Good quality co-design processes are more widely adopted.	Other practitioners, who were not involved in the project, apply the tools designed by the project.	CPNs work is further developed in light of their learning.
Engagement	Policy makers and practitioners hear about how good quality co-design can work.	Tools are shared more widely and practitioners share experiences of use of tools to colleagues..	CPNs engaging in learning and development.
Activities	Pilotlight is presented at conferences and widely promoted.	Practitioners use tools and adapt them as necessary	CPNs learn more about SDS, people's experiences of it and creative tools that can be used for involvement.
Inputs	Positive feedback about the Pilotlight co-design process and its results.	Tools including <ul style="list-style-type: none"> • Dementia Toolkit • Post Dementia Support Visit Letters • South Ayrshire Council Dementia Web Pages • Carer Support Planning Toolkit 	Learning and Development for Community Psychiatric Nurses (CPNs)



Direction of change

Figure 3- anticipated changes in future