Healthy lives equal healthy communities – the social impact of self-management
Foreword

Originally championed by the voluntary sector, lay-led self-management has been available in England since the 1990s. The Department of Health introduced the Chronic Disease Self Management Programme (CDSMP), the core programme for the Expert Patients Programme (EPP) into the NHS in England in 2002.

Since then, the focus on self care and self-management as a way of achieving greater engagement with health among the public has intensified, and there has been a move towards the fully engaged scenario put forward by the Wanless report.

This study, Healthy lives equal healthy communities – the social impact of self-management, looks at the wider benefits of self-management courses within communities in the north of England. It is based on Social Return On Investment (SROI) research carried out between April and June 2010. SROI is a widely accepted method for measuring the social or environmental value of a project or organisation. There are many things that we value, as a society and as individuals, that cannot be easily captured in economic terms. By bringing social and environmental value into decision making, SROI seeks to:

- reduce inequality
- prevent environmental degradation
- improve wellbeing.

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Having access to self-management programmes that encourage responsibility for health and well-being supports people to become re-engaged with the local community as productive citizens with meaningful activities, i.e., volunteering, education and employment.

“The course is made up of lots of little things but they all add up to make a huge difference. I understood that I needed to implement these new practices in all areas of my life and I was motivated to make things work as I wanted to feed back my success to the group the following week. Before the course, when faced with a challenge I used to think I was hitting a brick wall and would just give up. Now I use the action planning, problem solving and communication techniques I learnt on the course to make sure I overcome them.”  
Mel, Birkenhead

“I used drugs for 30 years, my life was in a mess and I couldn’t take it anymore. I contracted Hepatitis C because of my drug use and while in recovery, someone recommended the Expert Patients Programme Substance and Alcohol Misuse (SAM) course to me. It came at a crucial time as I really needed the support as it was still early days in my recovery. The things I learnt and the group I was part of helped my confidence to grow and I started to achieve things I hadn’t thought I was able to do before.”  
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Introduction

The coalition government has put forward the idea of a ‘Big Society’ where communities are engaged and proactive in deciding how local services are run and delivered. The idea of the engaged citizen is as important as the engaged patient if poor health and inequality are to be tackled effectively.

Our definition of poor health also needs to be wider than just physical health issues brought on by poor diet and lifestyle. It should include mental and emotional health and, in particular, issues around addiction and alcoholism, which can cause great damage to individuals, their families and the community.

This study, using the SROI evaluation process, looks at how community-based self-management programmes, when delivered to a target population, can have significant benefits for the individual and the wider community. It shows how the programmes create a shift from the individual being a cost and a burden to their community, to becoming a valuable resource that adds significant value.

Every day our actions and activities create and destroy value, changing the world around us. Although the value we create goes far beyond what can be captured in financial terms, this is, for the most part, the only type of value that is measured and accounted for. With the current cost pressure on health and social care, there is a tendency to look to the immediate cost benefit and ignore wider, less tangible benefits.

Service planning decisions are more effective, however, when based on complete information about full impacts. Taking these wider benefits into account is vital if we are to reduce the overall burden of public spending. This will become more important as public health budgets are transferred to local authorities and health and social care budgets become further integrated. A considerable amount of research, both quantitative and qualitative, has highlighted the personal health benefits of attending a self-management course. In February 2010, the Expert Patients Programme Community Interest Company (EPP CIC) published a report that also illustrated how economically beneficial targeted self-management could be for the NHS. It demonstrated a saving ratio of £3:1 – in other words, for every £1 invested, £3 was saved through improving participants’ quality of life and reducing avoidable hospital admissions.

Review of evidence

This study investigated the social impact of lay-led self-management programmes in the Wirral over a one year period. These courses focused on people recovering from drug and alcohol misuse. Untargeted generic Expert Patient programmes in Salford were also looked at in order to compare the social impact on different groups and the difference between targeted and untargeted approaches. There was a focus on the ancillary and lasting systematic impact.

It should be reiterated that this study did not investigate the many positive health and economic outcomes produced by lay-led self-management programmes, as these have been previously investigated and are well understood. This SROI study, whilst including all of the investment needed to run the programmes, therefore leaves aside much of the return gained through positive health outcomes and savings to the NHS.

It should also be highlighted that the impact of the self-management programmes included in the study varied considerably depending on the target community. Further investigation is needed to understand why these differences are so marked. However, the most prevalent outcomes were fairly universal and included:

- improved and new relationships with family and friends
- engagement in volunteering
- positive employment-related outcomes.

The study shows an overall social return on investment of 1.85:1
Methodology

In order to map the outcomes of the self-management courses effectively, participants were engaged in three different stages of the research:

1. Two representative focus groups of 5-6 people from the Wirral and Salford were brought together and interviewed with a set of open-ended questions. From these two interviews, a general Theory of Change was developed (See Figure 1). This went through a number of different iterations before it was ratified by all parties including a selection of participants.

2. From the Theory of Change, a second-stage questionnaire was developed and completed by a total of 52 participants (20% of the total).

3. The final stage of data collection involved re-engaging with a sample of the participants to test and finalise the various assumptions by the researchers on what could be attributed directly to the intervention.

Key Outcomes

It is clear that attending a lay-led self-management course triggers a cycle of positive re-enforcement that produces long-term changes in behaviour and confidence and reverses previous cycles of dependency and helplessness.

It can be seen in Figure 1, above, that the direct outcomes of attending a self-management course include an improved diet, meeting new people, gaining better control of one’s emotions and having increased self-awareness and self-worth. These are direct outcomes as they are taught as part of the EPP self-management ‘curriculum’.

![Figure 1: Theory of Change](image_url)
Key Outcomes

The main result of these direct outcomes is a general increase in confidence. Increased confidence leads to further outcomes, such as decreased anxiety, better sleep, the ability to try new things and increased motivation. This was confirmed at the second stage of the data-gathering process where participants were asked if there were any other important outcomes beyond those taught directly on the course. Comments included:

- “My confidence has grown. I have belief in myself now”
- “I’m more confident in managing my addiction”
- “Improved presentation skills, confidence, self-esteem and communication”
- “I’ve had a massive boost to my confidence.”

From here there are a variety of outcomes experienced by different participants. Many had improved relationships with family and friends, whilst others took part in various volunteering initiatives, further education or had positive job-related outcomes, such as increased work hours. Alongside this, there was a positive feedback loop back into increased confidence, which led to even better sleep, motivation, anxiety outcomes and so on.

Key outcomes were confirmed by the Wirral Drug and Alcohol Action Team (DAAT). The team found the EPP Substance and Alcohol Misuse (SAM) course to be effective, as it offers those in recovery from drug and alcohol misuse the opportunity to learn a range of skills that help them to successfully integrate back into the community.

Gary Rickwood, Strategy Manager with Wirral DAAT, comments: “The course provides valuable tools and techniques that can help to improve communication with family, friends and health professionals, raise self confidence and morale and increase the motivation to change. It also offers the chance to train as a SAM course tutor and to help gain the necessary skills to seek employment, voluntary work and further education.”

He adds: “The SAM course works alongside other programmes and courses commissioned by Wirral DAAT, working closely with these other partners. It is fully integrated with the wider treatment and recovery system and it is in this context that the course is able to achieve its maximum effectiveness.”

Case Study A

“Although I don’t have a successful business or the luxury trappings I once had, my quality of life is far better. I’ve been clean for nearly 12 months, I’ve taken on a mentoring role at a local college and I’m putting in the groundwork to get my career back on track.”

Case study A abused cocaine for 10 years until he lost his marriage, his once successful business and nearly his life after attempting suicide in 2009. His drug use began with regular use of ecstasy and amphetamines while out clubbing in his twenties. One night, too much ecstasy led to a decision to accept a line of cocaine which began his addiction. Funded by a good salary, he went from using cocaine once a month, to once a week, until it turned into a daily habit costing £300 a day.

He said: “It got to the point that I was just using cocaine in order to function. There was nothing moderating my habit – I was earning lots of money so it wasn’t difficult to get my hands on cocaine whenever I wanted.”

A five week spell in a private rehab clinic two years into his addiction didn’t help. He came out and within hours was on the phone to his dealer. He added: “At this point I wasn’t ready to accept I had a problem and all it did was make me become more deceptive as I would find ways to try and conceal my cocaine use from my family.”

After six years of cocaine misuse and at the age of 34, he was unable to maintain his professional career and had to sell his business – the proceeds of which he used to continue to fund his habit over the coming few years. After his money ran out, he began to self-harm and drink heavily which led him to obsess about suicide. He attempted to take his own life in August 2009 which left him with a choice to voluntarily admit himself to receive psychiatric help or be sectioned. He took the former option which saw the start of him turning his life around.

He received crisis help from a psychiatric hospital and was discharged after two weeks, fortunately with no serious or lasting mental health diagnosis. He then underwent an intensive drug rehabilitation programme with a local charity that provides support for people affected by substance misuse who also recommended him to EPP CIC’s Substance and Alcohol Misuse (SAM) course.

He said: “I was used to instant gratification when I used cocaine so after I stopped using, I was still looking for things to get better instantly, EPP CIC’s SAM course taught me how to break these things down into more manageable steps so I didn’t become frustrated when things didn’t happen at once. I learnt how to keep myself occupied with constructive activity and manage on a day-by-day basis through the techniques I learnt around goal setting and making action plans. Recovery takes time and the course gave me a sense of empowerment to achieve my goals.”

As part of his recovery and EPP CIC’s ethos to enable past participants to continue their own self-management journey, case study A has also successfully completed EPP CIC’s SAM Tutor Training and is looking forward to starting to deliver courses to others who are in a similar situation to his own.
Once individual outcomes had been collated they were scaled up to give outcomes for the total population. The modelled number of people experiencing each outcome can be seen in Figure 2, below.

These modelled outcomes are highly important when considering one of the main groups of participants on the self-management courses – people recovering from drug misuse, where activities such as theft and shoplifting may have been part of previous behaviour. Re-engagement with family, work, volunteering and community can be reasonably assumed as significant in preventing re-offending and relapse.

Changes experienced by self-management course participants are often life-long. However, in order to give a conservative estimate, the duration of change was modelled for five years. Again, in order to not over-claim the impact, the value for each of the outcomes was assumed to decline by 50% each year.

It should also be noted that feedback from local community organisations has not been included in the SROI calculation due to the limited time available for the analysis. This means the findings do not include the impact of the over 19,000 hours of voluntary work calculated to have taken place as a result of the EPP CIC self-management programmes.

Further, the study does not include other associated outcomes, such as reduced re-offending and increased employment, which could clearly offer significant benefits for the State.

Finally, it should be highlighted again that this study did not investigate the many positive health outcomes that happen as a result of the self-management programmes. The final ratio given overleaf, therefore, includes all of the investment while leaving out a substantial quantity of the return.

<table>
<thead>
<tr>
<th>Outcome Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stopped smoking</td>
<td>3%</td>
</tr>
<tr>
<td>Became an EPP tutor</td>
<td>8%</td>
</tr>
<tr>
<td>Started patient / community support groups</td>
<td>20%</td>
</tr>
<tr>
<td>Encouraged volunteering in others</td>
<td>31%</td>
</tr>
<tr>
<td>Paid employment related outcomes</td>
<td>26%</td>
</tr>
<tr>
<td>Taken part in volunteering</td>
<td>34%</td>
</tr>
<tr>
<td>Engaged in further education</td>
<td>36%</td>
</tr>
<tr>
<td>Improved relationships with existing friends</td>
<td>42%</td>
</tr>
<tr>
<td>Made and sustained new friendships</td>
<td>49%</td>
</tr>
<tr>
<td>Improved relationships with family</td>
<td>61%</td>
</tr>
</tbody>
</table>

Figure 2: Modelled total number of people experiencing each outcome

Case study B is in recovery from substance and alcohol misuse after 23 years of abuse. He recently attended a Substance and Alcohol Misuse (SAM) course, run by the Expert Patients Programme Community Interest Company (EPP CIC).

He said: “For years I felt marginalised by society and its rules and subsequently rebelled. I had, what is today known as, Attention Deficit Hyperactivity Disorder (ADHD) which I don’t believe was a known diagnosis back then. My condition led me to believe that I wasn’t normal and that to get attention from people I had to act a certain way.” He first began showing ADHD symptoms aged 6-7 years. This had an enormous effect on his education and resulted in him being expelled from three schools and being placed in a boarding school for maladjusted children. Despite his symptoms, he was never officially diagnosed.

Disruptive behaviour patterns followed him through all of his teens and into his early adult years and was, he believes, largely responsible for the substance and alcohol misuse, which then led onto two failed marriages and numerous sentences of imprisonment.

“My last prison sentence was for a period of eight years, which helped kick start my recovery and even though upon release I slipped back into substance and alcohol misuse, the therapy I had received had a great impact upon me and my lifestyle. To support my recovery I decided to attend a SAM course, run by EPP CIC. The course was very informative and gave me a sense of self achievement, it highlighted that I was in control of my own actions. I now feel that I have the knowledge to overcome my problems without having to rely on healthcare professionals, and I feel empowered and in control of my life again.”

Case study B successfully completed the SAM course and as a result is now employed by EPP CIC as a bank tutor. He has delivered 12 SAM courses to date.
The Social Return On Investment

This study showed an SROI ratio of 1.85:1. In other words, for every £1 invested in self-management programmes, £1.85 of social value was created. This delivered, in financial terms, £319,783 across all three programmes within the scope of the study. This is in addition to the £3:1 ratio already established in relation to direct health benefits.

As previously mentioned, the estimates on which this SROI calculation is based are deliberately conservative, in particular the assumption that outcomes will only last for five years. If all of the return were to be taken into account, the SROI ratio across the whole economy would be somewhere between 3.5:1 and 8:1.

The economic impact demonstrated by each of the three programmes varied dramatically. This can be seen in Table 1, below. Further investigation is needed to understand why these differences are so marked. However, it is suggested that the SAM course in the Wirral has a much higher return due to its specialised nature.

<table>
<thead>
<tr>
<th>Programme</th>
<th>Total Present Value</th>
<th>Investment</th>
<th>SROI Ratio</th>
<th>Health Service Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>SAM the Wirral</td>
<td>£212,255</td>
<td>£34,856</td>
<td>6.09</td>
<td>2</td>
</tr>
<tr>
<td>Salford EPP</td>
<td>£39,193</td>
<td>£79,000</td>
<td>0.50</td>
<td>3</td>
</tr>
<tr>
<td>Salford Self Care</td>
<td>£68,334</td>
<td>£58,746</td>
<td>1.16</td>
<td>3</td>
</tr>
<tr>
<td>For You</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1: SROI of the different EPP CIC self-management programmes

Who to target? Implications for commissioning and care pathways

This report, along with other published evidence on the effectiveness of psycho-social based self-management interventions for people living with long-term health conditions, clearly outlines the benefits to individuals, communities and to health and social care providers.

To maximise the effectiveness of funding it is important to understand who may benefit from this approach.

A sub-analysis of the main UK Random Controlled Trials (RCT’s) found that those people with poor baseline outcomes and who were experiencing psychological impact showed greatest gain.

The authors say, “The present results suggest that the Expert Patients Programme may have a protective effect on health-related quality of life for patients with poor health or low confidence. The course can help such patients to resist a deterioration in their health-related quality of life that would otherwise have occurred. If this is the case, the results have important implications.”

A study into causes of unplanned admissions states, “We sought to look specifically at health factors which we know are under-recognised in hospitals and primary care, and this showed that poor nutrition and depression are associated with higher health care use in this vulnerable subgroup.”

EPP CIC has worked to understand the profile of these service users and to adapt and develop its programmes to be more effective for these groups.

We have observed that the frequency of avoidable hospital admissions, service use and care requirements are not always consistent with the clinical severity of the condition. Often the level of disability or disease burden is disproportionate to the degree of actual impairment. This is demonstrated in the chart below:

Understanding impact-impairment/disability

Due to this, careful thought should be given if budgets are limited, where such programmes sit within a care pathway and how service users are referred to the programmes. Ideally they should be part of an integrated care and treatment plan.
Conclusion

This study looked at key outcomes for participants attending EPP lay-led self-management courses in The Wirral and Salford. Previous research has shown that self-management courses result in significant health benefits to participants and, as a result, real savings to the NHS. The aim of this study was to uncover the social value of attending a self-management course both for participants and their communities.

Using SROI techniques, the study found that direct course outcomes included improved diet, meeting new people, better control of feelings and increased self-awareness and self-worth. The key result of these outcomes was a general increase in confidence which, in turn, led to decreased anxiety, better sleep, a willingness to try new things and increased motivation.

As a result of these outcomes, participants felt able to make important life changes, such as improved relationships, volunteering, further education and positive job-related benefits, with obvious accompanying benefits for the wider community.

The calculation used to determine the SROI of these outcomes deliberately used conservative measures, setting the duration of change at five years and assuming a 50% drop-off rate for each of the outcomes. Based on these measures, the final calculation showed a return on investment ratio of 1.85:1. This translates into a social return value of £319,783 across all the programmes delivered during the term of the study.

The EPP CIC Substance and Alcohol Misuse (SAM) course delivered in the Wirral showed a particularly high SROI ratio of 6.09:1, possibly due to the closely tailored nature of the course.

References

i Securing our Future Health: Taking a Long Term View, Wanless, D, April 2002
ii Self Care reduces costs and improves health – the evidence, EPP CIC, February 2010
iii Predicting who will benefit from an Expert Patients Programme self-management course, D Reeves, A Kennedy, C Fullwood, P Bower, et al British Journal of General Practice, March 2008: 198-200
v With thanks to Professor Bob Lewin

Acknowledgements

The work was commissioned by EPP CIC. This project would not have been possible without the hard work and commitment shown by those directly involved. Most notably Jim Phillips, Director of Policy and Evaluation at EPP CIC, who scoped and guided the project; Pat Holmes, Business Development Manager, EPP CIC Northern Region; Scott Francis, Head of Self Care, Salford PCT; Julie Want, WISE Training Coordinator, Self Care Education Department, NHS Salford; and Vikki Brown, Quality Assurance Manager, Caring with Confidence, and finally Richard Kennedy, Head of Social Investment CAN who carried out the original research this report is based upon.

Welcoming the study, Miles Ayling, Director of Innovation and Service Improvement for the Department of Health, says: “The SROI research outcome clearly demonstrates the importance of community-led social rehabilitation initiatives. Self-management programmes like the EPP CIC Substance and Alcohol Misuse (SAM) course are significant and play an integral role in achieving the Government’s plans to improve care for people with long-term health conditions.”