

Expert Patients Programme

Community Interest Company

Healthy lives equal healthy

communities – the social impact

of self-management



Expert Patients
Programme

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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.”

Dougie, Wirral



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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.ⁱ

This study, *Healthy lives equal healthy communities – the social impact of self-management*, looks at the wider benefits of self-management courses in The Wirral. It is based on a Social Return On Investment (SROI) research carried out between April 2010 and November 2011. This research has been independently assured by The SROI Network and peer reviewed in *Self Care – The Journal of consumer-led health*.

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.

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 reportⁱⁱ 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.

The scope of this Social Return on Investment (SROI) study was to investigate the impact from April 2009 to March 2010 of the EPP CIC programmes in The Wirral which focused on participants with a substance and alcohol misuse history. This evaluative SROI shows that the value created between April 2009 and March 2010, as a result of the EPP CIC programmes in The Wirral, was £226,169.

This represents an SROI ratio of 6.49 : 1. For every £1 invested in the EPP programmes in The Wirral, approximately £6.50 of social value was created.

The most prevalent and most highly valued outcomes included:

- taking part in volunteering
- positive changes in employment
- improved relationships with family and friends
- general health improvements.

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.”*

Methodology

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

1. Representatives were brought together for a number of focus groups of 5-6 people and interviewed with a set of open-ended questions. From these 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 approximately 30% of the participants.
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.

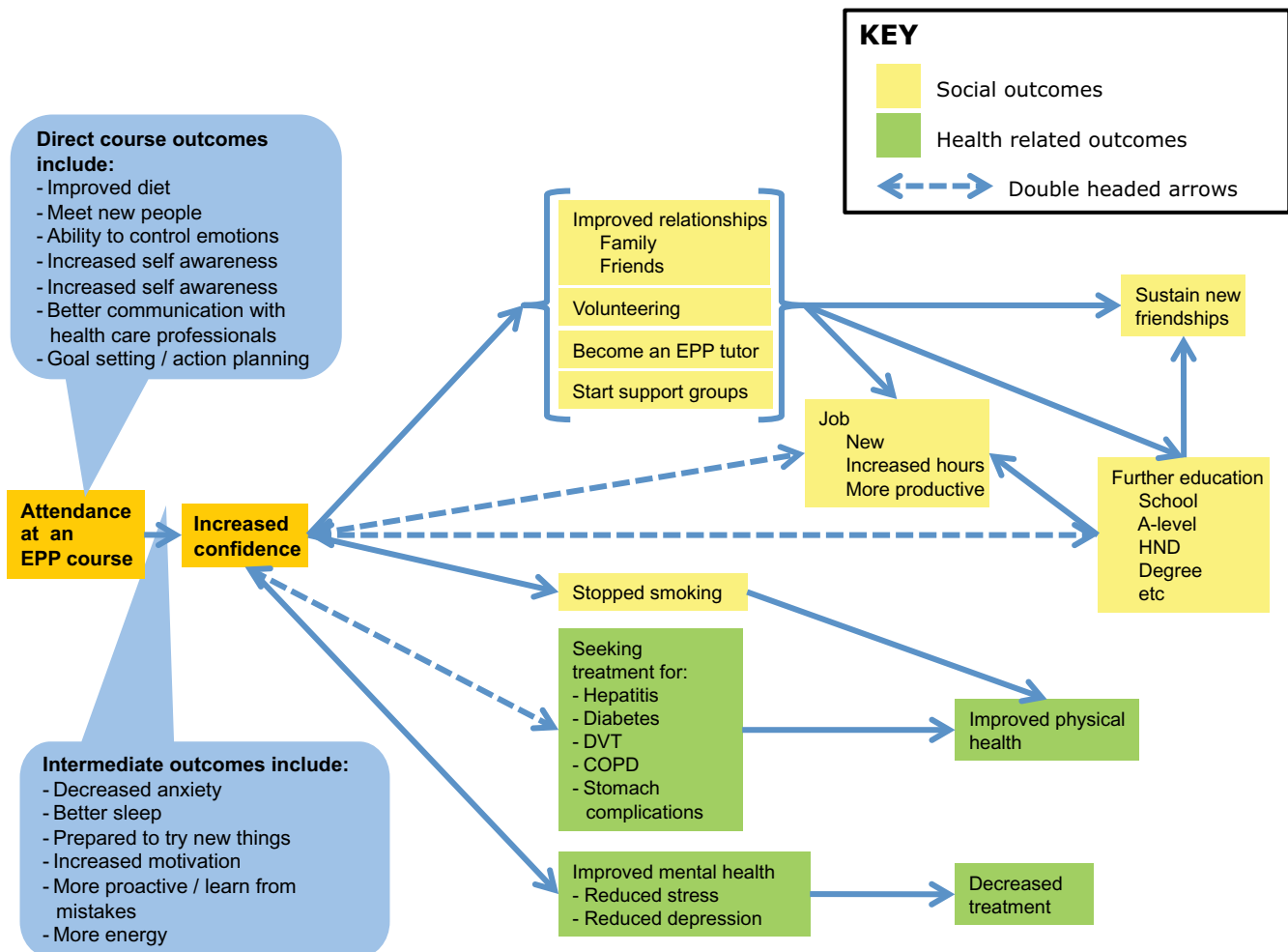


Figure 1: Theory of Change

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'.

Key Outcomes

The main result of these direct course outcomes is an increase in general confidence. This increase in confidence leads to further outcomes such as decreased anxiety, better sleep, the ability to try new things and increased motivation. This was confirmed in 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”
- “I started Hepatitis C treatment after the course and I now have more energy and my general health has improved”
- “I’m more able to do things now – I have an allotment now which is physically hard work”
- “I’m now more relaxed and approachable”
- “Skills and techniques I learned on the course have helped me to give up smoking”

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

From a health perspective, the increase in confidence and increased ability to engage with health professionals led to participants seeking treatment for a variety of related physical medical conditions. There was also positive impact on the participants’ mental health, particularly relating to decreased stress and depression.

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.

The study shows an overall social return on investment of 6.49 : 1

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.

Key Outcomes

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.

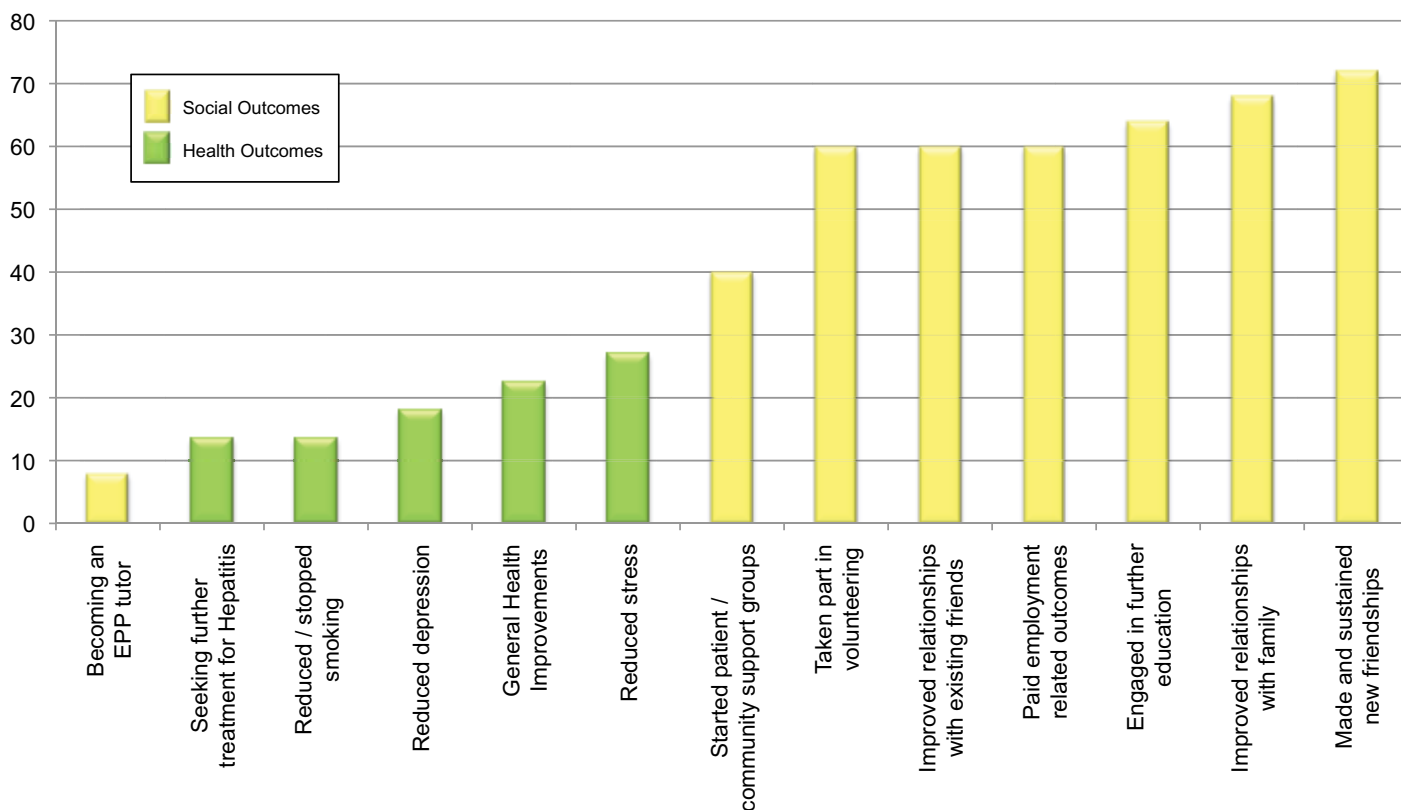


Figure 2: Modelled total number of people experiencing each outcome

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.

Widespread and diverse community impact was described by the participants as a result of the programmes in this study but these outcomes were not considered to be material due to the diverse and disparate nature of this impact. There may be additional outcomes for the state (for example reduced re-offending and increased employment), although due to the diverse nature of the impact these outcomes are not considered to be material for this study, but could be reviewed in a further cycle of the analysis.

Case Study B



“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 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.

This research has been independently assured by The SROI Network and peer reviewed in *Self Care – The Journal of consumer-led health*.

The Social Return On Investment

This evaluative SROI study shows that the value created between April 2009 and March 2010 as a result of the EPP CIC programmes in The Wirral was £226,169. This represents an SROI ratio of 6.49 : 1. For every £1 invested in the programmes, approximately £6.50 of social value will be created.

It is important to realise that the SROI ratio calculated is based on a number of key estimates and assumptions. Some of these assumptions have been tested in the sensitivity analysis. The SROI calculated changed to between 3.47 and 9.98 as alternative assumptions were tested.

Programme	Total Present Value	Investment	Ratio
SAM The Wirral (Social)	£191,975	£34,856	5.51
SAM The Wirral (Health)	£34,193	£34,856	0.98

Table 1: SROI of the different outcome categories

An earlier iteration of this study also looked at the social impact of EPP courses in Salford. This study showed a social return of £107,528 which represents a ratio of just under 1:1. This Salford study did not include any health outcomes.

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.



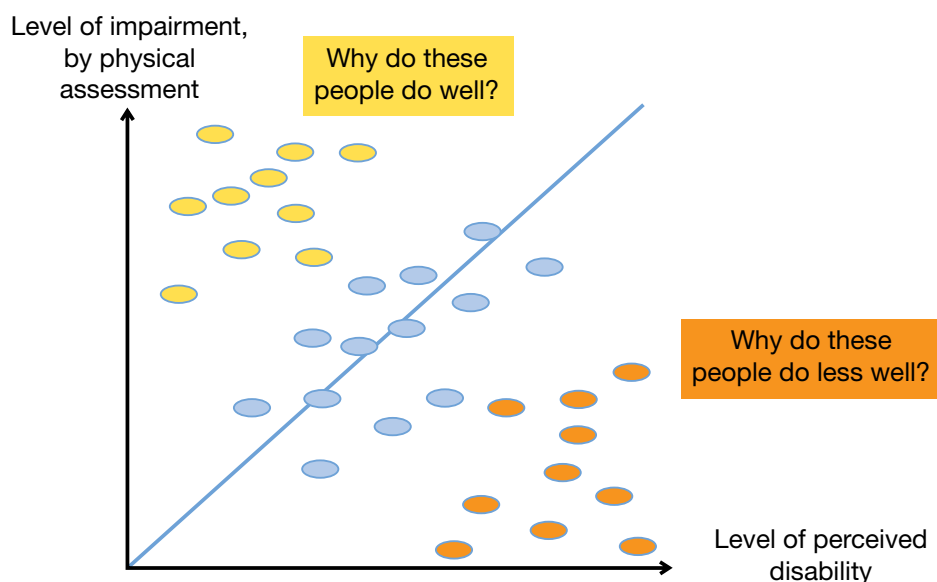
The authors say, “The present results suggest that the Expert Patients Programme may have a protective effect on health-related quality of life for patients with poor health or low confidence. The course can help such patients to resist a deterioration in their health-related quality of life that would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

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.”^{iv}

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^v 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, positive job-related benefits and general health improvements 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 6.49 : 1. This translates into a social return value of £226,169 across all the programmes delivered during the term of the study.

The benefits of the SROI process are significant and clear; by assigning financial values to social impacts, SROI is a valuable tool speaking a common language. The fact that the SROI calculation cannot take into account all the complexities of human / societal effect should not detract from the sure fact that considerable impacts are measurable with this methodology.

The SROI calculation and all figures presented in this report must be understood as part of the much wider picture of how EPP CIC changes individual lives and communities.

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.”*



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- v With thanks to Professor Bob Lewin
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Acknowledgements

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This report is based on original research completed by Richard Kennedy, Head of Social Investment at CAN.

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