Key Points

- The aim of this research was to evaluate the impact of the Big Lottery funded Stroke / Dementia project on its participants. The research also sought to assess the wider social value that the project is creating using a Social Return on Investment (SROI) analysis.

- Upstream’s Stroke / Dementia Support Project is aimed at reducing social isolation, depression, anxiety and stress of people who have dementia, had a stroke or are their carers in central Devon. The project offers social sessions comprising arts, craft, and gentle exercise. Upstream has introduced iPads to groups and developed inter-generational projects with school students.

- Social Return on Investment (SROI) is a framework for measuring and accounting for change in ways that are relevant to the people or organisations that experience or contribute to it. It seeks to capture social, environmental and economic outcomes and uses monetary values to represent them.

- Social inclusion makes an important contribution to good health. Social isolation and loneliness impact upon individuals’ quality of life and wellbeing, adversely affecting health and increasing their use of health and social care services.

- The evaluation includes data from 258 dementia / stroke / carers participants during the first 19 months of the project; of whom 212 also took part in 11 regular groups.

Key Findings

- Baseline assessments show that 23.7% report having a disability; 44.9% (n=91) report at least one long-term condition and 25% had two or more long-term conditions. Life satisfaction was lower than the national average and 67.8% (n=58) reported moderate or high levels of isolation.

- The evaluation found clear evidence of benefits accruing from the Dementia / Stroke Project to its participants. Before-and-after validated questionnaires revealed that between 61.8% and 73.3% said their life satisfaction, mental well-being or social inclusion had improved or stayed the same.

- Participant self-reports and project records provided evidence of wider positive impacts on: self-esteem, resilience to manage, recognition of their achievements and confidence to try new things.

- Participants and agency partners attribute the benefits of the Stroke / Dementia Support Project to a history of strong local engagement; to the flexible, holistic and social approach; and to the personal qualities of project staff and at Upstream.

- SROI analysis identified a positive social return for the investment made; for every £1 spent on the Stroke / Dementia Support Project there is £1.71 of social value.
**Upstream’s Stroke & Dementia Support Project**

The aims of the Stroke & Dementia Support Project are to reduce isolation, loneliness, depression, anxiety and stress. Participants feel they are not alone in their situation by being able to join a group, meet others, share experiences and encourage one another.

Upstream offers open group sessions that are held usually fortnight or monthly and during the evaluation period there were 3 taster groups and 11 regular groups. Groups are spread across rural, mid Devon to ensure they are more accessible to people who are socially isolated. Each session is run by an enabler and structured around social time, gentle physical activity and cognitive activity such as art, craft, quizzes and talks. iPad tablets have been provided offering a stimulating introduction to new technology.

There have been two pilot intergeneration groups involving 23 secondary students who spent two hours sessions with dementia groups to undertake a shared activity. For participants it was a chance to have 1:1 quality time with a young person and for the young people they gain insight into older people’s issues, and develop additional communication skills.

The project is open to anyone who has dementia or suffered stroke as well as their carers. Participants can self-refer to Upstream’s Stroke / Dementia Support Project or may be recommended by partner agencies.

**The Impact of Social Isolation**

Social isolation is characterised by an absence of social interactions, social support structures and engagement with wider community activities or structures. There is strong evidence that social isolation and loneliness impact upon individuals’ quality of life and wellbeing, adversely affecting health and increasing their use of health and social care services. Isolation, and the consequential lack of personal support networks, increases the burden on health services. In 45% of emergency admissions in the south west, older people lacked social contact, and over 80% were admitted from their own homes. Only 25% of such admissions were moderately or severely frail.

**Stroke**

The national clinical guidance for stroke recognises that much of the care a person needs after stroke comes from outside the health care system. Even for those who have only mild stroke, there are still life changing impacts and anxieties. Research suggests there is a relationship between improved recovery after stroke and the level of social contact and support available. In terms of meeting social needs, the national clinical guidance recognises that most healthcare focuses on peoples’ capabilities to go about daily living and part of this goal is to integrate into the community.

**Dementia**

Dementia refers to the decline in memory and other cognitive skills and which has a negative impact on daily living. By 2015 the Dementia UK estimates there will be 850,000 people with dementia in the UK. This equates to 1 in every 79 (1.3%) of the entire UK population, and 1 in every 14 (7.1%) of the population aged 65 years and over. Dementia is a significant cost to health services, estimated at £26.3 billion. There is also a significant social and well-being cost to carers.

---

1. Social Care Institute for Excellence. Preventing loneliness and social isolation: interventions and outcomes
2. Project Ariadne: Understanding the Reasons for Emergency Admissions of Elderly People: South West Academic Health Science Network 2014
3. National clinical guideline for stroke © Royal College of Physicians 2012
5. Ibid 4
The government’s current strategic aims to address dementia cover 3 over-arching themes of: driving improvements in health and social care, creating dementia friendly communities that understand how to help and better research to further understand the condition and its impact on society.

Research Aim and Methods
This research is part of a wider University of the West of England, Bristol (UWE)-led study of projects funded by the Big Lottery under the South West Well-being Programme (SWWB). In this study we sought to evaluate the impact of Upstream’s Dementia / Stroke Support Project on its participants, and examine the social value that the project is creating using Social Return on Investment (SROI) analysis. Finally we used the RE-AIM framework to review the learning from evaluation.

What is Social Return on Investment?
SROI is a framework for measuring and accounting for change in ways that are relevant to the people or organisations that experience or contribute to it. It seeks to measure social, environmental and economic outcomes and uses monetary values to represent them. SROI captures wider forms of value often left out of more traditional methods of economic evaluation such as cost benefit analysis.

Interest in social value has been raised by The Public Services (Social Value) Act (2013). The Act requires public bodies to consider how the services they commission and procure might improve the economic, social and environmental well-being of the area.

The act defines social value as “the benefit to the community from a commissioning/procurement process over and above the direct purchasing of goods, services and outcomes”.

The evaluation focuses on 19 months operation of the Stroke / Dementia Support Project (June 2013-December 2014) and includes all those who registered and took part in project activities during this time (n=258). Participants completed baseline and follow up questionnaires following enrolment. The measures covered life satisfaction, mental well-being (SWEMWBS) and social isolation (Friendship Scale) as well as staff recorded observations and achievements of participants and groups in their regular service reviews.

Project Participants
The main beneficiaries are 258 stroke / dementia participants and their carers who took part. Taster sessions were attended by 46 participants. 65% of participants suffered stroke / dementia and 35% were carers. Of 212 participants who attended group sessions, 127 attended at least twice and on an average of 4.3 occasions.

61.9% of participants were female and the average age is 76.7 years - reflecting Upstream’s work which is aimed towards older people. 23.7% report having a disability with mobility problems being the most common. 44.9% report at least one long-term condition; most commonly arthritis and disability. 25% had two or more long-term conditions.

Stroke Participant: “when it [stroke session] is close like early this morning or yesterday I was thinking tomorrow I am going out rather than lying here in bed every day.”

Outcomes for Social Isolation
Using the Friendship Scale tool, matched scores for the baseline and follow up questionnaires were available for 36 respondents. They show an increase in the mean score from 15.0 (SD 5.3) to 15.7 (SD 4.8) indicating reduced social isolation.

Use of a paired T test indicated that the change was not statistically significant across all the paired sets (p value = 0.26).
However more detailed examination of the data suggests that those who were socially isolated experienced greater improvement in Friendship Scale scores. For those described as socially isolated (n=16) showed an increase in average score from 9.9 (SD 3.0) to 12.6 (SD 3.5) and a t-test on this sample provided a statistically significant p value = 0.002. Although a degree of caution is needed due to the relatively small sample number an Effect Test (Cohen’s d)\(^8\) on the same data (d=0.81) supports the argument that for this cohort there was a large effect on their social isolation.

Amongst those with low friendship acuity at the baseline point (n 16), 75% felt less isolated at follow up. The greater the social isolation, the greater impact Upstream has upon participants in helping them to become socially connected.

**Outcomes for Mental Well-being**

Using the Short Warwick Edinburgh Mental Well-being Scale, the before and after matched sample (n=34) showed a rise in the mean score from 23.3 (SD 5.) to 24.2 (SD 4.8) indicating overall positive change in mental well-being. Nevertheless 55.9% (19/34) had improved mental well-being and 11.8% (4/34) reported their mental well-being was the same.

---

\(^8\) AI Therapy Statistics: Effect Size Test [https://www.ai-therapy.com/psychology-statistics/effect-size-calculator](https://www.ai-therapy.com/psychology-statistics/effect-size-calculator). A Large Effect is represented by a score >= 0.8
Additional Reported Outcomes

Through the data analysis, project reviews by staff and interviews with participants and stakeholders the following additional outcomes have been reported:

- Increased friendships
- A sense of belonging
- Motivated to try new things
- Signposted to advice, new activities and other social activities and opportunities
- Increased confidence and self-esteem
- Enabled use of ICT to maintain contact with family
- Volunteering
- Reduced depression
- Improved close-family relationships and recognition amongst carers that cared for people may still have greater abilities than they thought
- Respite opportunities for carers
- Empathy and increased resilience and able to cope with their conditions
- Feeling supported practically and emotionally

Due to the timeframe and limitations of the evaluation it is not always possible to know what happens or might happen to participants and carers in the longer term. Some indicators of further change have been identified from qualitative data collected for this study.

- Motivated to write an autobiography (n=1).
- Able to drive again (n=1).
- Taken up volunteering (n=1).
- Able to take up family responsibilities such as looking after grandchildren (n=2).
- Maintaining informal visits by a local occupational therapist has helped stroke participants to maintain longer term exercise (n=1).
- One participant joined an external exercise group (n=1).  
- Creative activities improve dexterity (reported by stakeholders as a general outcome).
- Secondary school students have gained an understanding of dementia and memory issues, improved their communication skills (n=13).
- Upskilling for staff (n = 6).
- Progression to new social activities (n=3 and reported by stakeholders as a general outcome).
- Supporting carers and cared for through signposting into other support networks such as Devon Carers, community enabling services, day opportunities.
- Reducing hospital admissions and GP visits (reported as a likely general outcome).

Carer: “The students give the session a much younger feel, something very good for my husband.”

Student: “The Memory Cafe helps our generation understand the impact of dementia and what we might face in future years.”

Carer: “The first time she came back from being with the 6th formers her enthusiasm was huge you could tell it in her eyes coming to life and I saw that in mum it was lovely.”

Upstream staff member observed: “B is now unable to use his computer at home and had not used a touch screen before. He was very happy to discover he could use the iPad very easily even though he has limited use of his hand. This was a great boost to his self-esteem as he said, if he purchased one it would enable him to keep in contact with his daughters at university via Skype.”

Social Return on Investment Analysis

The SROI analysis involves a stage-based process that involves: mapping outcomes from the perspective of stakeholders; defining the relationship between inputs, outputs and outcomes; evidencing outcomes and giving them a value; identifying those aspects of change that would have happened anyway or are a result of other factors to ensure that they are taken out of the analysis and then calculating the SROI.

Inputs

The total cost for Upstream’s Stroke / Dementia Support Project is £79,470 during the 19 months of the evaluation. This includes funding for Enablers, general overheads, and expenses associated with
delivering group-based sessions across the rural central Devon area.

**Outputs – Delivering the Project**

Records of group-based activities suggest there were 673 attendances at 86 sessions (excluding one off sessions) i.e. an average attendance of 7.8 participants.

There were 258 participants identified in the project suggesting a cost of £308.02 per participant. 212 attended regular group sessions (i.e. excluding one off demonstrations) of whom 127 attended at least twice and on average 4.3 times.

**Valuing outcomes**

In SROI we use financial proxies to estimate the social value of non-traded goods to different stakeholders. By estimating this value through the use of financial proxies and combining these valuations, we arrive at an estimate of the total social value created by an intervention.

The table at the end of this report provides a summary of all the outcomes included in the SROI analysis and the way in which they were valued.

**Calculating the Social Value**

SROI analysis found that the SROI ratio is 1:1.71. This means that the SROI analysis estimates that for every £1 spent on the Stroke / Dementia Support Project there is £1.71 of social value.

The total value of the impact for the 258 participants who received an intervention in the first 19 months of Stroke / Dementia Support Project is £136,275.49. The greatest benefit (84%) is to participants and their carers with the greatest value being in terms of improved mental well-being and outlook on life. The remaining 16% of value was attributed to a range of stakeholders.

The SROI analysis does not show value that would be expected to accrue to the National Health Service (NHS) and local authority social care services as a result of Upstream’s programmes. This is because there was limited evidence and availability of longer-term outcomes available from the data. However an alternative model suggests a possible value of £34,368.26 to NHS/social care and a ratio of 1:2.25; i.e. that there would be £2.25 of value for every £1 invested by Upstream. Further evidence of longer term outcomes would be needed to verify a value.

**Strengths and Limitations of the Research**

A key strength of this evaluation is the investment of time by Upstream to collect baseline and follow-up data from project participants. This means there was paired data for a sample of project participants that could be incorporated into the evaluation. Besides the stakeholder and participant interviews, Upstream rigorously collected qualitative material.

There are some limitations to this evaluation and SROI. One challenge has been that it was not possible (for ethical and practical reasons) to directly interview dementia participants and thus the views of the group might not be fully represented. Instead the SROI relies on the views of stakeholders and carers for those with dementia. Many participants have conditions that will deteriorate which may ultimately reduce their, or their carers, quality of life regardless of the success of Upstream’s Stroke / Dementia support Project.
Conclusion and Recommendations
In this evaluation and SROI report we have monetised the benefits of the Stroke / Dementia Support Project to its participants, students and other agencies working across communities in mid Devon. The report demonstrates a social return for the investment, and the feedback from participants and stakeholders clearly illustrate the programme’s positive impact to participants’ sense of inclusion, wellbeing and life circumstances. These findings fit with evidence earlier in the report demonstrating the importance of social interaction and reduced isolation in supporting people’s well-being.

Using the Re-AIM review framework we can summarise some key areas of learning from the evaluation:

- **Reach.** The project clearly reaches people who have had dementia or stroke and their carers who come from Upstream’s catchment area. Upstream is able to offer its service to a broad spectrum of abilities within the two cohorts from mild dementia / memory loss to more severe dementia and for stroke, those with very limited physical ability as well as those whose stroke has affected only the mind.

- **Effectiveness.** For some participants being able to recollect how things have changed would be challenging or impossible. Nevertheless there are base-line and follow-up evidence from a sample of participants that supports impacts on well-being, life satisfaction and isolation. There is some evidence to suggest that Upstream has a greater impact on social isolation amongst those who report being most isolated. Negative impacts were potentially to be found around the frequency of sessions. Missed attendance could re-ignite a sense of isolation and reduce mental well-being.

- **Adoption.** Upstream’s provides services in the local community using a range of community settings. This enables Upstream to integrate with or develop what might be happening in a local area. Partner organisations, both in the third sector and health, are supportive and provide referrals, and there is local promotion to allow people to refer themselves into a group. The inter-generational work with two secondary schools demonstrates wider community benefit and integration.

- **Implementation.** Upstream’s Stroke / Dementia Support Project draws upon the organisation’s mission, values and previous experience of supporting marginalised and isolated older people. Each programme has been tailored according to need but focuses on social contact with stimulation of body and mind through light physical activity, art and craft, talks and demonstrations. An innovation has been the introduction of i-Pad technology and the intergenerational links with students add an additional dimension to the support and were well received.

- **Maintenance.** Upstream staff have developed knowledge and skills to fine tune their offer. For many of the stroke/dementia cohort their underlying conditions will deteriorate or at best stabilise. Nevertheless, there is evidence of potential longer term benefits for some participants who have regained motivation and capacity to manage their conditions and do more. For carers there can be recognition that the person they care for may be more capable than realised.

---

What is the RE-AIM Framework?
RE-AIM is a useful framework for reviewing community projects that have public health goals.

- **Reach**
  Does the intervention reach the target population?

- **Effectiveness**
  Does the intervention achieve the assumed goals, without negative outcomes?

- **Adoption**
  Was the intervention broadly adopted at the community level?

- **Implementation**
  Was the intervention consistently implemented at a reasonable cost?

- **Maintenance**
  Does the intervention have the ability to be sustained, with long-lasting effects?

---

A key interest for Upstream is securing alternative funding. This report provides a tool for working with local commissioners and other funding bodies to identify possible sources of funding to secure ongoing delivery of the project.

It also highlights ways in which improvements could be made to the project to maximise benefit to individuals and other local projects and services offered by Upstream.

Key recommendations arising from this study are:

**Recognising and valuing what Upstream achieves more widely.** Collectively, Upstream staff have extensive knowledge of community resources and statutory organisations in their area of operation. Participants valued the informal advice, guidance and signposting they received. It is felt that Upstream under-recognises the value it plays in this role.

**Planning future services.** Increasing the frequency of sessions in each location might improve the average attendance rate and thus reinforce the positive health and well-being outcomes that could be achieved.

Upstream undertook a mapping and scoping exercise to identify what services could be delivered. Clarity of purpose, aims and outcomes of planned activities may help define their scope more rigorously. While reducing isolation is a recurrent aim of Upstream’s activities, it is harder for observers to always identify what is the main purpose of an activity. Using iPads as a tool for helping participants with memory issues is a good example of the effectiveness a focus can have on participants.

Upstream might benefit from using a tool, such as the Re-AIM framework as a way of supporting the planning and evaluating activities which would reinforce its quantitative and qualitative data outcomes collection.

**Building evaluation into the planning stage.** Upstream has a good evolved system for capturing qualitative outcomes which capture good stories. During this Well-being programme Upstream has introduced more rigorous capture of quantitative data and it is recommended they should embed monitoring end evaluation in all activities including in the planning of future services. Further evidence collected around health would enable Upstream to reinforce their value to the NHS, CCGs and social care stakeholders identified in this SROI analysis.

**Intergenerational projects.** The intergenerational work between Upstream groups and students received positive feedback. Working with a smaller number of students more consistently is likely to build students confidence and knowledge more sustainably and for older participants greater familiarity might foster greater recollection and improve their social cohesion.

---

This study was led by Phil Aubrey (Well UK) with Dr Richard Kimberlee (UWE), Mat Jones (UWE), and Olly Biggs (UWE).

We would like to acknowledge and thank all the Upstream Staff – particularly Justin Smallwood, Claire Whewell and Francis Anson - participants and partner agency staff linked to the Stroke / Dementia Support Project for their support and assistance in undertaking this research.

April 2015

For full Evaluation & SROI Report and details of the wider evaluation of the SWWB programme see [http://westbank.org.uk/](http://westbank.org.uk/) or contact matthew.jones@uwe.ac.uk.

For details on the Upstream contact upstreamuk@hotmail.com.
### Social Return on Investment – outcomes included and their values

<table>
<thead>
<tr>
<th>Outcome</th>
<th>n</th>
<th>Financial Proxy</th>
<th>Value per participant / unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants and their carers reporting improved outlook, better understanding of their condition, having something to look forward to</td>
<td>68 of 127</td>
<td>Life Coaching Course. Managing Yourself and Personal Effectiveness Training Course</td>
<td>£480</td>
</tr>
<tr>
<td>Reduced isolation, enjoying the company, someone to talk to</td>
<td>74 of 127</td>
<td>Cost of joining a social group plus participation costs</td>
<td>£120.00</td>
</tr>
<tr>
<td>Increased mental well-being</td>
<td>71 of 127</td>
<td>Cost of CBT to build psychological resilience and self esteem</td>
<td>£930.00</td>
</tr>
<tr>
<td>New volunteering by participant</td>
<td>1 of 1</td>
<td>Estimated from Average Hourly Rate £12.92 per hour in England, 2 hrs per week for 40 weeks</td>
<td>£1033.60</td>
</tr>
<tr>
<td>Reduced anxiety, feeling more relaxed or reduced depression</td>
<td>9</td>
<td>Cost of relaxation therapy based on a 40/50 minutes session in Plympton, Devon £25. Average attendance for stroke / dementia 3.4 sessions</td>
<td>£107.50</td>
</tr>
<tr>
<td>A sense of feeling up to date by using the iPads, a realisation that new technology is not beyond reach, able to recollect memories, people, and places from the past</td>
<td>56 of 127</td>
<td>Cost of 2 hrs Introduction to iPad – 1/2 Day £95 Course (pro rata) run by Amseys IT company</td>
<td>£47.50</td>
</tr>
<tr>
<td>Respondents reporting the value of time for themselves or opportunity for time to do something else or not be responsible whilst in groups</td>
<td>456</td>
<td>Cost of a typical sitting service for 3 hrs (taking into account time of carer to arrange service and the value carers place on the respite time) Cost per hour of typical sitting service. Devon Carers survey 82% of carers prepared to pay £14-£16</td>
<td>£45.00</td>
</tr>
<tr>
<td>Carers and stakeholders reporting that the participants are able to do more than realised. Creating ‘quality moments’</td>
<td>19</td>
<td>Equivalent to a meal out (Carvery + beverage + desert for 2 at Marston’s Red Deer, Crediton)</td>
<td>£60.06</td>
</tr>
<tr>
<td>A chance to try a taster or one-off activity</td>
<td>131</td>
<td>Cost of attending a ‘one off’ 2 hour drawing course or a tile painting craft course in Devon</td>
<td>£13.00</td>
</tr>
<tr>
<td>Participants are better informed / signposting to other advice / information and support</td>
<td>70</td>
<td>Web searches for average hourly cost of physio, speech therapy, Citizen’s Advice, nutrition</td>
<td>£50.00</td>
</tr>
<tr>
<td>Improved skills amongst staff to deliver Dementia, Stroke and use iPad technology in sessions to stimulate participants. 6 Staff attending 8 courses.</td>
<td>n/a</td>
<td>a)Actual amount spent on training by Upstream during the evaluation period for all participants b) in house Stroke Awareness; cost of 3 hr session at</td>
<td>£808.00</td>
</tr>
<tr>
<td>Outcome</td>
<td>n</td>
<td>Financial Proxy</td>
<td>Value per participant / unit</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>----</td>
<td>--------------------------------------------------------------------------------</td>
<td>------------------------------</td>
</tr>
<tr>
<td>25 attendances</td>
<td></td>
<td>Bourneville College £30 per person x5</td>
<td></td>
</tr>
<tr>
<td>Upstream supported by 23 volunteer students to support participants on a 1:1 basis to achieve Upstream aim to help those suffering from dementia and to help them continue to be part of the community without being stigmatised or prompting withdrawal from society</td>
<td>23</td>
<td>Estimated from Average Hourly Rate £12.92 per hour in England, 3 hrs volunteering including briefing and travel of volunteers</td>
<td>£38.76</td>
</tr>
<tr>
<td>Increased awareness of dementia, memory issues and communication skills amongst students</td>
<td>23</td>
<td>Cost of attending a Dementia Awareness Workshop run by the Alzheimer's Society</td>
<td>£114.00</td>
</tr>
<tr>
<td>Increased capacity of referral partner to support more clients across Devon</td>
<td>n/a</td>
<td>Stroke Association Cost of 0.5 FTE Stroke Support Coordinator for 19 months</td>
<td>£20,199.00</td>
</tr>
<tr>
<td>Use of community transport facilities, revenue to private taxi firms</td>
<td>34</td>
<td>Cost of a 3 mile journey, 6 mile round trip a) 5 x Community transport (including special lifting Gear, Tiverton &amp; District Community Transport Association £3 per journey b) 3 x Taxi Your Taxi Meter per journey = £7.50. Weighted average £5.06 per journey or £10.13 round trip</td>
<td>£10.13</td>
</tr>
</tbody>
</table>