

# Community Engagement – approaches to improve health and reduce health inequalities

# **Cost-consequence analysis**

**Health Economics 3** 

**Optimity Advisors February 2016** 





# **Table of Contents**

Ackn	owledgements	
	ors & contact details	
	sary	
	troduction	
1.1.	Background	
1.2.	Aims	
1.3.	Community engagement	
2. M	lethods	8
2.1.	Selection of case studies	8
2.2.		
2.3.	Details of case studies	
Life i	s Precious	
	ey findings	
	nected Communities (C2) – Positively Local	
	ey findings	
	s Gypsy and Traveller Exchange (GATE)	
	ey findings	
3. Co	onclusions	43



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# Glossary

Cost-consequence analysis (CCA) "One of the tools used to carry out an economic evaluation. This compares the costs (such as treatment and hospital care) and the consequences (such as health outcomes) of a test or treatment with a suitable alternative. Unlike cost-benefit analysis or cost-effectiveness analysis, it does not attempt to summarise outcomes in a single measure (such as the quality-adjusted life year) or in financial terms. Instead, outcomes are shown in their natural units (some



of which may be monetary) and it is left to decision-makers to determine whether, overall, the treatment is worth carrying out"<sup>1</sup>.

**Comparator**: The standard intervention against which an intervention is compared in a study. The comparator can be no intervention (for example, usual or standard care) $^2$ .

**Peer/lay delivered**: This involves services engaging communities, or individuals within communities, to deliver interventions. In this model, change is believed to be facilitated by the credibility, expertise or empathy that the community member can bring to the delivery of the intervention.

**Collaboration**: This involves engagement with communities, or members of communities, in strategies for service development, including consultation or collaboration with the community about the intervention design. Such models hold the underlying belief that the intervention will be more appropriate to the participants' needs as a result of incorporating stakeholders' views.

**Empowerment**: Empowerment models require that the health need is identified by the community and that they mobilise themselves into action. These models have the underlying belief that, when people are engaged in a programme of community development, an empowered community is the product of enhancing their mutual support and their collective action to mobilise resources of their own and from elsewhere to make changes within the community.

**Community health champions**: Individuals who are trained and supported to help and motivate their friends, family, neighbours and colleagues to lead more healthy lives.

<sup>1</sup>NICE Glossary. <a href="https://www.nice.org.uk/Glossary?letter=C">https://www.nice.org.uk/Glossary?letter=C</a> [Accessed 26/05/15]

<sup>2</sup>NICE glossary. <a href="https://www.nice.org.uk/Glossary?letter=S">https://www.nice.org.uk/Glossary?letter=S</a> [Accessed 20/05/15]



# 1. Introduction

# 1.1. Background

NICE has been tasked with developing guidance on Community engagement - approaches to improve health and reduce health inequalities'.

Optimity Advisors has been commissioned to undertake an economic analysis to support the development of the NICE guideline on 'Community engagement - approaches to improve health and reduce health inequalities' in order to update Public Health Guideline 9, published in 2008.

The work to update the guideline is divided in three streams:

- Community engagement: a report on the current effectiveness and process evidence, including additional analysis (stream 1);
- Community engagement: UK qualitative evidence, including one mapping report and one review of barriers and facilitators (stream 2);
- An economic analysis cost effectiveness review and economic model (stream 3).

Optimity Advisors has been commissioned to undertake the Stream 3 work package. Initially, it comprised three components, a précis of the economic evidence reported in "Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis" (O'Mara et al., 2013<sup>3</sup>), a rapid update review and an economic model. However, in discussion with NICE and the committee, the development of an economic model has been replaced with 3 cost-consequence analyses and a review of the social return on investment (SROI) evaluations. This report relates to the cost-consequence analyses.

The detailed information about other streams is presented elsewhere and is not replicated here. A detailed specification of the guidance is provided in the scope<sup>4</sup>.

# 1.2. Aims

The aim was to conduct an economic analysis to answer three research question in the area of community engagement:

<sup>3</sup>O'Mara-Eves A, Brunton G, McDaid D, Oliver S, Kavanagh J, Jamal F et al. (2013). Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis. Public Health Research 1(4). Available at:

http://www.journalslibrary.nihr.ac.uk/ data/assets/pdf file/0006/94281/FullReport-phr01040.pdf

<sup>4</sup>National Institute for Health and Clinical Excellence; Public Health Guideline; Community engagement: approaches to improve health and reduce health inequalities - Guideline scope: <a href="https://www.nice.org.uk/guidance/gid-phg79/documents/community-engagement-update-final-scope-2">https://www.nice.org.uk/guidance/gid-phg79/documents/community-engagement-update-final-scope-2</a>



**Question 1**: How cost-effective are community engagement approaches at improving health and wellbeing and reducing health inequalities?

**Question 2**: How cost-effective are community engagement approaches at encouraging people to participate in activities to improve their health and wellbeing and realise their capabilities – particularly people from disadvantaged groups?

**Question 3**: What processes and methods help communities and individuals realise their potential and make use of the all the resources (people and material) available to them?

To answer these questions, a convenience sample of three interventions was selected from a review that mapped the literature on current and emerging community engagement policy and practice in the UK conducted by stream 2. Only those interventions with independent evaluations were considered for possible inclusion. Leeds Beckett University provided Optimity with a set of evaluation reports for consideration. Three initiatives were identified as suitable for inclusion on the basis that they had evaluation reports which reported an economic analysis or contained sufficient information that they could be readily adapted as a cost consequence analysis (CCA). As these covered the three categories of intervention identified in previous research (peer/lay delivered, collaboration and empowerment), it was agreed with NICE that these would form the basis of the current report. For each initiative, we undertook economic analysis assessing the **cost** of each intervention, its **effects** in terms of benefits to health, wellbeing and/or reducing inequalities, and the possible subsequent **impact** that a potential improvement could generate. No formal quality assessment was undertaken of this small group of studies as the range of evidence was considered to be too limited for meaningful application of the tools used by NICE. However, it is intended that the detailed summaries contained in this report will give the reader sufficient information to assess the quality of the evidence on which the CCAs have been based.

The three case studies were selected to provide one example in each of the three categories of community engagement considered in the review of cost-effectiveness evidence, namely peer/lay-led interventions, those characterised by collaboration and those centred on the concept of empowerment. In relation to the three questions identified above, the examples presented here are more informative with respect to questions 1 and 2 than question 3.

# 1.3. Community engagement

Community engagement is defined as "an umbrella term encompassing a continuum of approaches to engaging communities of place and/or interest in activities aimed at improving population health and/or reducing health inequalities"<sup>5</sup>. A more detailed definition has been proposed by the Evidence for Policy and Practice Information (EPPI) team which co-authored the O'Mara-Eves et al. (2013) report. The term community engagement applies to:

<sup>5</sup>Popay J (2006). Community engagement for health improvement: questions of definition, outcomes and evaluation. A background paper prepared for NICE. London: National Institute for Health and Care Excellence.



"Community-level interventions or interventions that involve a group of people connected by geographies, interests or identities in the design, development, implementation or evaluation of an intervention. Participants must include members of the public or patients (more than health professionals, pharmacists, public health nurses, other health semi-professionals) that are involved in the design, delivery or evaluation of the intervention. The treatment administrator/provider is more important for determining community engagement than the intervention setting. Intervention types to be excluded are legislation, policy and pharmacological."

The scope for the guideline associates community engagement with activities by which people can improve their health and wellbeing by helping to develop, deliver and use local services. Community engagement can involve varying degrees of participation and control. For the purposes of the economic analysis, NICE is particularly interested in the three main theoretical approaches to community engagement identified in the review cited above by the Evidence for Policy and Practice Information and Coordinating Centre (EPPI-Centre). These are:

- Peer/lay delivered interventions.
- Collaboration between health and other statutory services and communities.
- Interventions centred on the concept of empowerment.

The following definitions are drawn from the O'Mara-Eves et al. (2013) study previously cited.

# Peer-/lay-delivered interventions.

"This involves services engaging communities, or individuals within communities, to deliver interventions. In this model, change is believed to be facilitated by the credibility, expertise or empathy that the community member can bring to the delivery of the intervention."

#### Collaboration.

"This involves engagement with communities, or members of communities, in strategies for service development, including consultation or collaboration with the community about the intervention design. Such models hold the underlying belief that the intervention will be more appropriate to the participants' needs as a result of incorporating stakeholders' views."

# Empowerment.

"Empowerment models require that the health need is identified by the community and that they mobilise themselves into action. These models have the underlying belief that, when people are engaged in a programme of community development, an empowered community is the product of enhancing their mutual support and their collective action to mobilise resources of their own and from elsewhere to make changes within the community."



# 2. Methods

# 2.1. Selection of case studies

Based on the case studies identified by the review team (workstream 2), the PHAC and NICE project team identified three intervention types for inclusion in the cost-consequence analysis, (CCA) on the grounds that these interventions represent each community intervention type — peer/lay delivered, collaboration and empowerment. The intervention selected to represent each category was agreed with the PHAC and the NICE project team. The following interventions were selected for economic analysis:

- Peer/lay delivered Life is Precious
- Collaboration Connected Communities (C2): Positively Local
- Empowerment Leeds Gypsy and Traveller Exchange (GATE)

For these interventions, we carried out cost-consequence analysis (CCA). The economic analysis was conducted in line with NICE's "Methods for the development of NICE public health guidance" <sup>6</sup>.

The case studies included in the CCA were classified by workstream 2 into these 3 categories. In the next section we present the details of the three programmes. A brief overview of each programme is followed by a table summarising the results of the CCA.

# 2.2. Analysis methodology

CCA was deemed to be the most suitable type of economic analysis for this topic, and this was agreed with the PHAC and the NICE project team.

CCA compares costs (i.e. the cost of implementing a programme or intervention) with its consequences, such as health outcomes, quality of life, wellbeing, or cost savings. "Unlike cost-benefit analysis or cost-effectiveness analysis, it does not attempt to summarise outcomes in a single measure (such as the quality-adjusted life year) or in financial terms. Instead, outcomes are shown in their natural units (some of which may be monetary) and it is left to decision-makers to determine whether, overall, the treatment is worth carrying out" In CCA, a 'balance sheet' of monetary, quantitative, and descriptive consequences is presented.

CCA was thus selected as:

<sup>&</sup>lt;sup>6</sup> National Institute for Health and Care Excellence, 2012. Methods for the development of NICE public health guidance (third edition).

http://www.nice.org.uk/article/pmg4/chapter/6-incorporating-health-economics

<sup>&</sup>lt;sup>7</sup>NICE Glossary. <a href="https://www.nice.org.uk/Glossary?letter=C">https://www.nice.org.uk/Glossary?letter=C</a> [Accessed 26/05/15]



- There is limited strong statistical evidence on the relationships between intervention effects and subsequent impacts, compounded by the variety of ways in which effects are reported;
- The complex nature of the intervention and the lack of a clear comparator makes it very difficult to definitively assess cause and effect and report a statistically significant outcome.

Costs of each intervention (over and above its comparator) were assessed through Optimity's own research (where not reported by the intervention paper), drawing on published unit costs from standard national sources such as the Personal Social Services Research Unit<sup>8</sup> (PSSRU) and studies of similar interventions. Costs were calculated using a bottom-up approach, i.e. building up the total intervention cost from the components described in the intervention paper.

Consequences were included as reported by the intervention papers.

Impacts were reported in two ways: financial consequences describe the potential cost savings to the health service from improved health, quality of life etc. and descriptive consequences outline the likely impact both to the individual in terms of health and wellbeing which might encompass outcomes relating to health, education, crime and other impacts and the community as a whole, such as social cohesion (as reflected, for example, in public attitudes). While intervention effects are reported only from the original study paper, consequences draw on the literature identified in our systematic review as well as any other available data found through searching specifically for each CCA.

Consequences are reported in as much detail as the data from the source studies allow, and, where quantified impacts are reported in the original evaluations, they are presented here. Costings combined information available from the evaluation reports with Optimity's illustrative assumptions about, for example, staff time required to implement the programme and standard sources of unit costs.

It was decided to colour code the outcomes (consequences) of the project into the traffic light system where green indicates a positive outcome, amber no difference or a non-statistically significant finding and red indicates a negative outcome, as well as provide a description of consequences, and any financial impacts that could be calculated. However, due to the nature of the case studies, only positive consequences are reported (although generally without tests of statistical significance); therefore, the consequences listed in the summary tables have been shaded green. The following sections provide a brief overview of each case study followed by the summary tables.

# 2.3. Details of case studies

<sup>8</sup>Personal Social Services Research Unit. Unit Costs of Health and Social Care 2014. <a href="http://www.pssru.ac.uk/project-pages/unit-costs/2014/">http://www.pssru.ac.uk/project-pages/unit-costs/2014/</a> [Accessed 26/05/15]



# Life is Precious

# Peer/lay delivered

#### **Project description**

Life is Precious is a cancer awareness and health improvement project using creative arts approach to engage with local minority ethnic communities in Dudley. The project aims to involve communities in a dialogue around cancer and focused on three languages – Urdu, Punjabi and Arabic. Life is Precious aims to increase awareness of cancer signs and national screening programmes for cervical, breast and bowel cancers. The age groups "...reflected those eligible for the three cancer screening programmes; cervical (25-64), breast (50-70) and bowel (60-74)"<sup>9</sup>. Additionally, the programme aimed to recruit community health champions that could help to increase cancer awareness in the community after the completion of the creative arts workshops.

# **Project delivery**

There were a number of stakeholders involved in the project. An initial meeting to give an overview of the project was attended by representatives of Dudley PCT and the Walsall creative development team. Working alongside community representatives, a series of consultation meetings was held to plan the creative arts workshops. Community leaders/representatives and individuals from local minority ethnic communities took part in a number of these arts based cancer awareness workshops A 5 week programme of workshops of one 3 hour workshop per week was scheduled and it was advised that attendance at all workshops would be beneficial. A community health improvement team was responsible for overseeing, co-ordinating and managing the programme. The Walsall Council creative development team was responsible for recruiting and managing the freelance artists that took part in the workshops. The Principal Arts and Health Officer managed and led a team of 6 freelance artists. Where possible, the artists met with community representatives to share their ideas for the content of the workshops. Interpreters were also involved in the delivery of the project. The delivery team consisted of artists, community leads, interpreters and representatives from the PCT and creative development team. Primary care staff were responsible for the accuracy of cancer awareness information. A multi-agency reference group consisting of the Public Health Inclusion Team, the Dudley Council Adult & Community Learning Team and the Performing Arts Team gave advice on project delivery. An arts network also supported a PhD student in carrying out a qualitative evaluation of the programme.

The programme consisted of five phases:

**Phase 1:** Community engagement and recruitment of participants; during this phase the project leads (from Dudley PCT and Walsall creative development team) set up the project to meet the needs, interests and logistic requirements of the participants.

<sup>9</sup>Curno P, Parker R, Pritchard J, Sogi P(2012). Life is Precious; Dudley Cancer Awareness Arts & Health Project; Evaluation Report September 2011



**Phase 2**: Creative participatory arts process; the workshops were designed to engage community members through arts. In total, 55 arts workshops were held and 106 participants took part. The words and images created by the participants during the workshops were transformed into fridge magnets and z-cards (foldable guides) in three languages (Urdu, Punjabi and Arabic). These cards and magnets were disseminated through numerous events to local communities.

**Phase 3**: Identifying the outcomes; both quantitative and qualitative evaluations were performed to measure project outcomes. To measure awareness, the Cancer Awareness Measure (CAM) survey was used. The CAM survey was administered before and after the project. The CAM survey was used to capture the effectiveness of the arts intervention and its effect on cancer symptom awareness. In addition, the Short Warwick Edinburgh Mental Well-Being Scale (SWEMWBS) was used to measure changes in feeling and attitudes of the participants. SWEMWBS was administrated before and after the workshops.

**Phase 4**: Sharing and celebrating; during this phase, the participants had a chance to meet different community groups and share their art work.

**Phase 5**: Building a legacy; after the creative arts workshops has been completed, the final objective of the project was to recruit community health champions, from the participants in the workshops, who would continue awareness raising activities within their communities. A consultation exercise was conducted with participants in the workshops to ascertain whether they would be interested in becoming community health champions. Additional training was developed for workshop participants who volunteered to become health champions to assist them with their role. In total, 54 project participants expressed an interest in becoming community health champions.

# **Project outcomes**

The key project outcomes as reported in the evaluation report prepared by Curno et al. (2012) and cited above are summarised below. Full details of the outcomes are given in the table.

# Increased awareness;

The programme found that there was an increase in the awareness of signs and symptoms of cancers and an increase in the proportion of participants who reported that they would make an appointment straight away with a doctor to discuss a sign/symptom. Knowledge of cancer causes and national screening programmes also increased.

# Engagement in the community groups;

"The project was successful in empowering and engaging with the identified community groups and participants demonstrated a high level of commitment with good attendance at most of the Sessions. Doing art together helped participants to identify how they could support each other in order to promote the messages and help build relationships. Participants bonded when they considered ways in



which they could engage with the wider community about cancer awareness issues, and were able to adapt the cancer messages to make them relevant to their community" (Curno at al., 2012).

#### Personal development;

The participants reported increases in the cumulative well-being scores (measured by SWEMWBS). The artists that helped participants during the workshops thought that the participants developed confidence in expressing their identity. Participants also learnt and practised their communication skills.

## • The role and value of art;

The participants learned creative techniques. Workshops helped people to relax. It was found that participants "...felt more comfortable signing up for creative sessions than they would for a health session" (Curno et al., 2012). More details on the outcomes of the programme are presented in the cost-consequence analysis sections.

#### Ingredients for success;

A number of steps were identified for success in the implementation of the programme. The steps included: planning and preparation, engagement, delivery, production of resources, evaluation and sustainability.

#### Aspect of community engagement:

The project brings together the minority ethnic groups and communities together to improve cancer awareness. For example, step 2 of the programme is all about engaging with the community.

## Type of community engagement – peer/lay delivered:

This project was classified in this category due to the following characteristics: The intervention is delivered by a number of stakeholders to increase cancer awareness and also aims to encourage participants to "...support each other, and consider how they can share messages with the wider community". Additionally, the programme recruits Community Health Champions that are part of the community and deliver health and wellbeing interventions within their own community.

# **Key findings**

Table 1 presents key findings from the cost-consequence analysis, including a short description of the intervention, study outcomes as reported directly in the text (whereby green indicates a positive outcome; amber no difference or a non-statistically significant finding; and red indicates a negative outcome), as well as a description of consequences, and any financial consequences that could be calculated. As with the other examples, only green shading has been applied to the consequences for this case study.

More detail on the way in which these results were calculated is given below Table 1.



Table 1: Key findings<sup>10</sup>

Table 1: Key findings <sup>10</sup>							
Intervention	Curno P et al., 2012. Life is Precious; Dudley Cancer Awareness Arts & Health						
paper	Project; Evaluation Report September 2011						
Intervention	Life is Precious						
Study design	Case study						
	<ul> <li>Theoretical approach: peer/lay delivered</li> </ul>						
	Arts approach						
	Conducted in the UK						
	<ul> <li>Dudley PCT and Walsall Council</li> </ul>						
	<ul> <li>In three languages: Urdu, Punjabi and Ar</li> </ul>	In three languages: Urdu, Punjabi and Arabic					
	The programme aimed to highlight the						
	programmes:						
	<ul><li>Cervical cancer, ages 25-64</li></ul>						
	<ul><li>Breast cancer, ages 50-70</li></ul>						
	o Bowel cancer, ages 60-74						
Intervention	Life is Precious is a cancer health improve	ement project	commiss	ioned by the			
description	Dudley Public Health Community Health Imp			-			
	creative arts approach to engage local people from minority ethnic communities in						
	a dialogue around cancer.						
	The president and a set to set as						
	<ul><li>The project set out to:</li><li>Increase awareness of cancer signs and</li></ul>	sumptoms and	d tha imaa	ertance of the			
			•				
	three national screening programmes for						
	Involve minority ethnic communities in t	-		ges to inform			
	the content and design of cancer awaren	iess resources	;				
	Recruit Community Health Champions.  Life is Presidues Ontimity adjountaines (A phases only evaluding recruitment of						
Intervention cost	Life is Precious: Optimity calculations (4 phases only, excluding recruitment of						
	Community Health Champions): £169 per participant or £17,870 (106 participants)  Recruitment of Community Health Champions: £2,700 per Champion or £145,800						
	(54 Champions)						
	All 5 phases of <i>Life is Precious</i> : £1,544 per participant or £163,670 in total (106						
	participants)						
Study outcomes	Awareness measured by CAM survey						
(as per Curno,	Increase in awareness of warning signs and symptoms of cancer following the						
2012)	workshops measured by the Cancer Awareness Measure (CAM) survey						
	A higher proportion mentioned signs/symptoms of:						
	Input	Pre	Post	Change			
	Lump/swelling	49%	63%	14%			
	Pain	20%	37%	17%			

<sup>&</sup>lt;sup>10</sup>Curno P, Parker R, Pritchard J, Sogi P (2012). Life is Precious; Dudley Cancer Awareness Arts & Health Project; Evaluation Report September 2011. Dudley: Dudley Public Health Department.



Change in bowel/bladder habits 3% 14% 11% Change in appearance of a mole 0% 12% 12% A higher proportion were aware when prompted of the signs/symptoms of: Persistent unexplained pain 46% 66% 20% Unexplained bleeding 53% 69% 16% Change in bowel/bladder habits 51% 69% 18% There was a substantial increase in the proportion of participants saying they would make an appointment with a doctor straightaway (i.e. in the next 1-3 days) to discuss a sign/symptom:  Pre Post Change 46% 71% 25% There were also increases in the awareness of potential cancer causes and in awareness of the NHS screening programmes for cervical, breast and bowel cancer A higher proportion mentioned unprompted the following potential causes:  Input Pre Post Change Smoking 53% 73% 20% Drinking alcohol 25% 34% 9% Exposure to another person's smoke 19% 37% 18% Eating red or processed meat 5% 25% 20% A higher proportion were aware when prompted of the potential causes of: Eating red or processed meat 54% 71% 17% Being overweight 64% 75% 119% Getting sunburnt more than once as a child 51% 66% 15% Being over 70 years old 44% 71% 27% Infection with HPV 37% 61% 24% Engagement measured through number and make-up of participants, observations and feedback from artists and participants Doing art together helped participants to identify how they could support each other in order to promote the health messages and help build relationships Participants bonded when they considered ways in which they could engage with the wider community about cancer awareness issues, and were able to adapt the cancer messages to make them relevant to their community As a result of the project 54 of the 106 participants expressed an interest in becoming a Community Health Champion to share the information they had learnt	Bleeding		7%		34%	26%	
Change in appearance of a mole 0% 12% 12% A higher proportion were aware when prompted of the signs/symptoms of:  Persistent unexplained pain 46% 66% 20% Unexplained bleeding 53% 69% 16% 16% Change in bowel/bladder habits 51% 69% 18% There was a substantial increase in the proportion of participants saying they would make an appointment with a doctor straightaway (i.e. in the next 1-3 days) to discuss a sign/symptom:  Pre Post Change 46% 71% 25% Post Change 46% 71% 25% Post Change 46% 71% 25% Post Change 46% Post Post Change 46% Post Post Post Post Post Post Post Post					14%	11%	
A higher proportion were aware when prompted of the signs/symptoms of:  Persistent unexplained pain			0%				
Persistent unexplained pain  Unexplained bleeding  Change in bowel/bladder habits  There was a substantial increase in the proportion of participants saying they would make an appointment with a doctor straightaway (i.e. in the next 1-3 days) to discuss a sign/symptom:  Pre  Post  Change  46%  71%  25%  There were also increases in the awareness of potential cancer causes and in awareness of the NHS screening programmes for cervical, breast and bowel cancer A higher proportion mentioned unprompted the following potential causes:  Input  Pre Post Change  Smoking  Drinking alcohol Exposure to another person's smoke 19%  Tay Eating red or processed meat 5% 25%  A higher proportion were aware when prompted of the potential causes of: Eating red or processed meat 5% 25%  Eating red or processed meat 54% 71%  Reing overweight 64% 75% 11%  Getting sunburnt more than once as a child 51% 66% 15% Being over 70 years old 44% 71% 27% Infection with HPV Engagement measured through number and make-up of participants, observations and feedback from artists and participants It is reported that the project was successful in empowering and engaging with the identified community groups (as indicated by artists' reflections) and participants demonstrated a high level of commitment with attendance at most of the sessions described as 'good' as reported by the artists  Doing art together helped participants to identify how they could support each other in order to promote the health messages and help build relationships  Participants bonded when they considered ways in which they could engage with the wider community about cancer awareness issues, and were able to adapt the cancer messages to make them relevant to their community  As a result of the project 54 of the 106 participants expressed an interest in			of the s	signs			
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feelings and thoughts that best described participants' experiences over the	Increase in the cumulative well-being scores after the workshops, based on the						
previous two weeks (mean Short Warwick Edinburgh Mental Well Being Scale							



(SWEMWBS) score (no significance test is reported):				
Pre	Post	Change		
28	30	2		

The artists felt participants had developed in confidence and used the art work to express their own identity. The author also claims that there was an evidence of participants becoming more empowered (artists' reflections are reported in this context) and willing to address cultural barriers

Participants learnt and practised their communication skills; this made them more confident about sharing the messages from the project in the future

Increase in skills, confidence and well-being supported 54 participants of a total of 106 to identify themselves as potential Community Health Champions

Others felt that learning a new creative skill helped slow down the

learning around cancer awareness (the reasons for this were not explored); but rather than prevent this learning from happening, the creative process helped provide space and time for people to reflect upon the message they had been given and learn at a pace that was more comfortable and less pressurised. Once they had learnt more about the issues, the participants were enthusiastic about suggesting ways to help spread the messages. The artists felt they had developed in confidence and used the art work to express their own identity. No detail or explanation is given on this

The report claims that there was also evidence of participants becoming more empowered and willing to address cultural barriers. The breast cancer awareness sessions used a breast model to aid the discussions around being breast aware (but culturally inappropriate for some). However, no further evidence or explanation is given to support this claim

# *Life Is Precious* Celebration Event

From the 64 participants who attended the event the following feedback was gained:

- 64 (100%) reported that they had spoken to or met somebody new at the event
- 55 (85%) reported that they had the opportunity to see the art work produced by the other groups
- 57 (89%) reported that they felt proud of their art work
- 48 (75%) reported that they had learnt something new from attending specifically:
  - Trying a new art form (25%);
  - Gaining new information (19%);
  - Receiving health information (1%);
  - Linking to local services (1%);
  - Finding out about new opportunities/volunteering/funding (1%);
  - Other learning, no details given (37%).

# Financial consequences

It is difficult to assess how the project outcomes can be translated into financial benefits; however, following the workshops of the *Life is Precious* programme, the report presents some evidence of increased awareness of cancer symptoms. Arguably, increased awareness can be potentially translated into some financial



benefits. Cancer services cost the NHS £5bn per year. Inclusion of the cost of loss productivity increases this cost to £18.3bn and represents the cost to society as a whole 11. This is indicative of other potential benefits which might be possible from the programme.

It is found that 4 in 5 people with a cancer diagnosis are affected by the financial impact of cancer and on average incur costs of £570 per month. "Almost one in three (30%) people living with cancer experienced a loss of income as a result of their diagnosis; those affected lose, on average, £860 a month" <sup>12</sup>.

The average cost of inpatient hospital treatment for breast cancer up to 7 years following the diagnosis is estimated at £10,200 $^{13}$ .

The mean total cost per patient with bowel cancer was estimated at £8,808<sup>14</sup>.

"Screening has reduced cervical cancer incidence and prevents  $^{\sim}4,500$  deaths each year. Estimated savings are £36,000 per life saved and £18,000 per cancer prevented"  $^{15}$ .

# Descriptive consequences

Recognition and early detection of cancer increases the chances of successful treatment. "Increased awareness of possible warning signs of cancer, among physicians, nurses and other health care providers as well as among the general public, can have a great impact on the disease. Some early signs of cancer include lumps, sores that fail to heal, abnormal bleeding, persistent indigestion, and chronic hoarseness. Early diagnosis is particularly relevant for cancers of the breast, cervix, mouth, larynx, colon and rectum, and skin" <sup>16</sup>. The WHO emphasise the two elements of early detection: education to promote early diagnosis and screening.

Early detection of breast cancer is likely to result in better outcomes. Detection at early stages can mean that the disease is smaller and still confided in the breast. Early detection can save lives<sup>17</sup>.

http://www.macmillan.org.uk/Documents/CancersUnequalBurden 2014.pdf [Accessed 14/04/2015]

 $\underline{\text{http://www.cancer.org/acs/groups/cid/documents/webcontent/003165-pdf.pdf}} \ [Accessed \ 14/04/2015]$ 

<sup>&</sup>lt;sup>11</sup>Gov.uk. Policy; Cancer research and treatment. <a href="https://www.gov.uk/government/policies/helping-more-people-survive-cancer">https://www.gov.uk/government/policies/helping-more-people-survive-cancer</a> [Accessed 14/04/2015]

<sup>&</sup>lt;sup>12</sup>Macmillan. Cancer's Hidden Price Tag. <a href="http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pdf">http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pdf</a> [Accessed 14/04/2015]

 $<sup>^{\</sup>rm 13}\text{Macmillan.}$  2014. Cancer's Unequal Burden. The reality behind improving cancer survival rates.

<sup>&</sup>lt;sup>14</sup>York Health Economic Consortium University of York, School of Health and Related Research University of Sheffield. 2007. Bowel Cancer Services: Costs and Benefits. Summary Report to the Department of Health

<sup>&</sup>lt;sup>15</sup>Parliamentary Office of Science and Technology. 2008. Postnote. Cervical cancer. <a href="http://www.parliament.uk/documents/post/postpn316.pdf">http://www.parliament.uk/documents/post/postpn316.pdf</a> [Accessed 14/04/2015]

<sup>&</sup>lt;sup>16</sup>WHO. Early detection of cancer. <a href="http://www.who.int/cancer/detection/en/">http://www.who.int/cancer/detection/en/</a> [Accessed 14/04/2015]

<sup>&</sup>lt;sup>17</sup>American Cancer Society. Breast Cancer Prevention and Early Detection.



HPV can lead to cervical cancer development. Early prevention and detection of the condition can help avoid the development of the cancer in the future. Outreach, community mobilization, health education and counselling are recognised to be essential in disease prevention<sup>18</sup>.

It has been estimated that the cervical screening programmes have reduced mortality rates by 62% over the period 1987-2006<sup>19</sup>.

Early screening and detection is important in outcomes for bowel cancer. Screening tests can find polyps that can be removed before they develop into cancers. "The relative 5-year survival rate for colorectal cancer when diagnosed at an early stage before it has spread is about 90%. But only about 4 out of 10 colorectal cancers are found at that early stage. When cancer has spread outside the colon, survival rates are lower"<sup>20</sup>.

# Additional consequences

As noted, Life is Precious phase aims to recruit Community Health Champions (CHCs). However, no additional details are given on potential benefits of the CHCs programme. In this section, we summarise some potential benefits of a CHC programme, while recognising that the objectives of the programme may differ from those of Life is Precious.

"Health Champions are people who, with training and support, voluntarily bring their ability to relate to people and their own life experience to transform health and well-being in their communities" <sup>21</sup>.

#### Impact on communities:

- The programme brought people together and established new group activities

   "...to walk, share problems, go swimming, cook etc. and so champions were helping to foster social networks" (White et al., 2010<sup>22</sup>);
- The programme is found to have a positive impact on health, such as weight loss, increased exercise and stopping smoking (reported by Champions) and social outcomes, such as social cohesiveness and help integrating people into their community (White et al., 2010);

http://apps.who.int/iris/bitstream/10665/144785/1/9789241548953 eng.pdf [Accessed 14/04/2015]

http://www.cancer.org/acs/groups/cid/documents/webcontent/003170-pdf.pdf [Accessed 14/04/2015]

<sup>&</sup>lt;sup>18</sup>WHO. 2014. Comprehensive Cervical Cancer Control; A guide to essential practice; Second edition.

<sup>&</sup>lt;sup>19</sup>Parliamentary Office of Science and Technology. 2008. Postnote. Cervical cancer. <a href="http://www.parliament.uk/documents/post/postpn316.pdf">http://www.parliament.uk/documents/post/postpn316.pdf</a> [Accessed 14/04/2015]

<sup>&</sup>lt;sup>20</sup>American Cancer Society. Colorectal Cancer Prevention and Early Detection.

<sup>&</sup>lt;sup>21</sup>Altogether better. Unlocking the power of communities to transform lives. Health Champions. <a href="http://www.altogetherbetter.org.uk/health-champions">http://www.altogetherbetter.org.uk/health-champions</a> [Accessed 14/04/2015]

<sup>&</sup>lt;sup>22</sup>White J, South J, Woodall J, Kinsella K. 2010. Altogether Better Thematic Evaluation – Community Health Champions and Empowerment. Centre for Health Promotion Research; Leeds Metropolitan University



- CHCs can be effective health promoters while working in their own communities (White et al., 2010);
- It is found that the programme is effective in tackling health inequalities (White et al., 2010);
- Volunteering is found to bring health and social benefits to those involved (White et al., 2010);
- It has been found that, for each £1 of investment in volunteer support, small voluntary organisations can gain between £2-8 of value from their volunteers (South et al., 2010<sup>23</sup>);
- Champions can help communities to stop smoking, lose weight and/or take up walking, and achieve improved mental health and wellbeing (White et al., 2010);

Positive impacts were seen among Champions themselves (White et al., 2010):

- As a consequence some champions lost weight and became more physically active;
- There was a positive impact on mental health;
- Quality of life improved;
- General wellbeing improved;
- "Some new champions felt they had already gained a lot from just doing the training, not just in knowledge and skills but in networks and friends";
- Champions gained self-awareness, confidence and a strong sense of achievement;
- Better knowledge and awareness of health issues.

To illustrate the benefits which have been reported for Community Health Champions, in this section we have included the findings of two Social Return on Investment (SROI) analyses conducted for Community Health Champions programmes in Sheffield and Calderdale.

Sheffield Community Health Champions Social Return on Investment (SROI) analysis found that for every £1 spent £6.22 (£5.51-£7.21\*) is generated in benefits (Turner and McNeish, 2010<sup>24</sup>).

*Calderdale Community Health Champions SROI* analysis found that for every £1 spent £36.11 (£31.93-£40.90\*) is generated in benefits (Turner and McNeish, 2010).

<sup>\*</sup>Sensitivity range

<sup>&</sup>lt;sup>23</sup>South K, Raine G, White J. 2010. Community Health Champions. Evidence Review. Centre for Health Promotion Research; Leeds Metropolitan University.

<sup>&</sup>lt;sup>24</sup>Turner D, McNeish D. 2012. Altogether Better Final Programme Evaluation Report 2012; Executive Summary. A report produced by DMSS Research and Consultancy for Altogether Better



There were a number of measurement scales used to measure the effect of the Life is Precious intervention. The table below presents the details of these scales.

**Table 2: Measurement scale** 

Scale	Measure	Understanding	Source
Cancer Awareness Measure (CAM)	The topics assessed in the CAM include: awareness of warning signs, anticipated delay in seeking medical help, barriers to seeking medical help, awareness of risk factors, risk factor ranking, awareness of incidence, awareness of common cancers, and awareness of NHS screening programmes	The CAM comprises 9 questions with a total of 47 items:  Warning signs (10 items) (Q1 + Q2)  Seeking help (1 item) (Q3)  Barriers to seeking help (11 items) (Q4)  Emotional — embarrassed, scared, worried about what the doctor might find, confidence discussing symptom (4 items)  Practical — too busy, too many worries, transport (3 items)  Service — wasting time, difficulty making appointment, difficulty talking to doctor (3 items)  Other — verbatim (1 item)  Risk factors 12 items (Q5 + Q6)  Cancer and age (1 item) (Q7)  Most common cancers (6 items) (Q8)  NHS screening programmes (6 items) (Q9)  Knowledge (3 items)	Curno P et al., 2012; CRUK, 2011 <sup>25</sup>
Short Warwick Edinburgh Scale for Measuring Mental Wellbeing (SWEMWBS)	This scale measures any changes in feelings and attitudes associated with wellbeing	<ul> <li>Age of first invitation (3 items)</li> <li>Participants scored (out of 5) the following statements based on their feelings and thoughts that best described their experience over the last two weeks:         <ul> <li>I've been feeling optimistic about the future</li> <li>I've been feeling useful</li> <li>I've been feeling relaxed</li> <li>I've been dealing with problems well</li> <li>I've been feeling close to other people</li> </ul> </li> </ul>	Curno P at al., 2012

 $<sup>^{25}</sup>$ Cancer Research UK, 2011. Cancer Awareness Measure (CAM); Toolkit (version 2.1).

 $\underline{\text{http://www.cancerresearchuk.org/sites/default/files/health professional cancer awareness measure toolkit version 2.1~09.02.11.pdf}$ 



	I've been able to make up my own mind about things	
	Scoring = 1: None of the time, 2: Rarely, 3:	
	Some of the time, 4: Often, 5: All of the	
	time	

# **Cost of the Life is Precious intervention**

In the subsequent tables we present the cost calculation for the programme. The table below presents the resources utilised in the project. The data is summarised from Curno et al. (2012).

Table 3: Resources per phase (all from Curno et al., 2012)

Community groups 6 Arts workshops 55 Participants 106 Community Health Champions recruited 54 The words and images developed by the community participants through the workshops informed the content and design of z-cards and fridge magnets which were produced in Urdu, Punjabi and Arabic Disseminated through outreach events, appropriate venues and those working within health/local community information Phase 1: Community engagement and recruitment of participants  **Representatives from Dudley PCT and Walsall Creative Development Team attending a Community Cohesion Meeting, which was attended by community representatives and organisations from across the Dudley borough  Jun-Sept 2010 the project leads undertook extensive development work to shape the project to meet the needs, interests and logistical requirements of the recruited participating groups  **Phase 2: Creative participatory arts process**  The *Principal Arts and Health Officer* managed and led a team of 6 freelance artists. Planning meetings were held with each artist and, where logistically possible, the artists met with community representatives to share their ideas for the creative delivery  **Before the workshops began the artists, community representatives and interpreters* supporting the sessions attended a training and briefing session led by the *Cancer Health Improvement Coordinator**  Weekly workshops delivered between Sept-Dec 2010  **Sept.**  **Defails below**  **Details below**	Input	Unit
Arts workshops Participants  Community Health Champions recruited The words and images developed by the community participants through the workshops informed the content and design of z-cards and fridge magnets which ware produced in Urdu, Punjabi and Arabic Disseminated through outreach events, appropriate venues and those working within health/local community  Phase 1: Community engagement and recruitment of participants  Representatives from Dudley PCT and Walsall Creative Development Team attending a Community Cohesion Meeting, which was attended by community representatives and organisations from across the Dudley borough  Jun-Sept 2010 the project leads undertook extensive development work to shape the project to meet the needs, interests and logistical requirements of the recruited participating groups  Phase 2: Creative participatory arts process  The Principal Arts and Health Officer managed and led a team of 6 freelance artists. Planning meetings were held with each artist and, where logistically possible, the artists met with community representatives to share their ideas for the creative delivery  Before the workshops began the artists, community representatives and interpreters supporting the sessions attended a training and briefing session led by the Cancer Health Improvement Coordinator	General	
Participants  Community Health Champions recruited  The words and images developed by the community participants through the workshops informed the content and design of z-cards and fridge magnets which were produced in Urdu, Punjabi and Arabic  Disseminated through outreach events, appropriate venues and those working within health/local community  Phase 1: Community engagement and recruitment of participants  Representatives from Dudley PCT and Walsall Creative Development Team attending a Community Cohesion Meeting, which was attended by community representatives and organisations from across the Dudley borough  Jun-Sept 2010 the project leads undertook extensive development work to shape the project to meet the needs, interests and logistical requirements of the recruited participating groups  Phase 2: Creative participatory arts process  The Principal Arts and Health Officer managed and led a team of 6 freelance artists. Planning meetings were held with each artist and, where logistically possible, the artists met with community representatives to share their ideas for the creative delivery  Before the workshops began the artists, community representatives and interpreters supporting the sessions attended a training and briefing session led by the Cancer Health Improvement Coordinator	Community groups	6
Community Health Champions recruited  The words and images developed by the community participants through the workshops informed the content and design of z-cards and fridge magnets which were produced in Urdu, Punjabi and Arabic  Disseminated through outreach events, appropriate venues and those working within health/local community  Phase 1: Community engagement and recruitment of participants  Representatives from Dudley PCT and Walsall Creative Development Team attending a Community Cohesion Meeting, which was attended by community representatives and organisations from across the Dudley borough  Jun-Sept 2010 the project leads undertook extensive development work to shape the project to meet the needs, interests and logistical requirements of the recruited participating groups  Phase 2: Creative participatory arts process  The Principal Arts and Health Officer managed and led a team of 6 freelance artists. Planning meetings were held with each artist and, where logistically possible, the artists met with community representatives to share their ideas for the creative delivery  Before the workshops began the artists, community representatives and interpreters supporting the sessions attended a training and briefing session led by the Cancer Health Improvement Coordinator	Arts workshops	55
The words and images developed by the community participants through the workshops informed the content and design of z-cards and fridge magnets which were produced in Urdu, Punjabi and Arabic  Disseminated through outreach events, appropriate venues and those working within health/local community information  Phase 1: Community engagement and recruitment of participants  Representatives from Dudley PCT and Walsall Creative Development Team attending a Community Cohesion Meeting, which was attended by community information  Phase 2: Creative participating development work to shape the project leads undertook extensive development work to shape the project to meet the needs, interests and logistical requirements of the recruited participating groups  Phase 2: Creative participatory arts process  The Principal Arts and Health Officer managed and led a team of 6 freelance artists. Planning meetings were held with each artist and, where logistically possible, the artists met with community representatives to share their ideas for the creative delivery  Before the workshops began the artists, community representatives and interpreters supporting the sessions attended a training and briefing session led by the Cancer Health Improvement Coordinator	Participants	106
workshops informed the content and design of z-cards and fridge magnets which were produced in Urdu, Punjabi and Arabic  Disseminated through outreach events, appropriate venues and those working within health/local community  Phase 1: Community engagement and recruitment of participants  Representatives from Dudley PCT and Walsall Creative Development Team attending a Community Cohesion Meeting, which was attended by community representatives and organisations from across the Dudley borough  Jun-Sept 2010 the project leads undertook extensive development work to shape the project to meet the needs, interests and logistical requirements of the recruited participating groups  Phase 2: Creative participatory arts process  The Principal Arts and Health Officer managed and led a team of 6 freelance artists. Planning meetings were held with each artist and, where logistically possible, the artists met with community representatives to share their ideas for the creative delivery  Before the workshops began the artists, community representatives and interpreters supporting the sessions attended a training and briefing session led by the Cancer Health Improvement Coordinator	Community Health Champions recruited	54
Disseminated through outreach events, appropriate venues and those working within health/local community  Phase 1: Community engagement and recruitment of participants  Representatives from Dudley PCT and Walsall Creative Development Team attending a Community Cohesion Meeting, which was attended by community representatives and organisations from across the Dudley borough  Jun-Sept 2010 the project leads undertook extensive development work to shape the project to meet the needs, interests and logistical requirements of the recruited participating groups  Phase 2: Creative participatory arts process  The Principal Arts and Health Officer managed and led a team of 6 freelance artists. Planning meetings were held with each artist and, where logistically possible, the artists met with community representatives to share their ideas for the creative delivery  Before the workshops began the artists, community representatives and interpreters supporting the sessions attended a training and briefing session led by the Cancer Health Improvement Coordinator  No further information  No further information  Postalls below  Details below  Details below	The words and images developed by the community participants through the	No further
Disseminated through outreach events, appropriate venues and those working within health/local community  Phase 1: Community engagement and recruitment of participants  Representatives from Dudley PCT and Walsall Creative Development Team attending a Community Cohesion Meeting, which was attended by community representatives and organisations from across the Dudley borough  Jun-Sept 2010 the project leads undertook extensive development work to shape the project to meet the needs, interests and logistical requirements of the recruited participating groups  Phase 2: Creative participatory arts process  The Principal Arts and Health Officer managed and led a team of 6 freelance artists. Planning meetings were held with each artist and, where logistically possible, the artists met with community representatives to share their ideas for the creative delivery  Before the workshops began the artists, community representatives and interpreters supporting the sessions attended a training and briefing session led by the Cancer Health Improvement Coordinator		information
Within health/local community  Phase 1: Community engagement and recruitment of participants  Representatives from Dudley PCT and Walsall Creative Development Team attending a Community Cohesion Meeting, which was attended by community information  Jun-Sept 2010 the project leads undertook extensive development work to shape the project to meet the needs, interests and logistical requirements of the recruited participating groups  Phase 2: Creative participatory arts process  The Principal Arts and Health Officer managed and led a team of 6 freelance artists. Planning meetings were held with each artist and, where logistically possible, the artists met with community representatives to share their ideas for the creative delivery  Before the workshops began the artists, community representatives and interpreters supporting the sessions attended a training and briefing session led by the Cancer Health Improvement Coordinator  No further information  Details below  Details below  Details below		
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Jun-Sept 2010 the <i>project leads</i> undertook extensive development work to shape the project to meet the needs, interests and logistical requirements of the recruited participating groups  Phase 2: Creative participatory arts process  The <i>Principal Arts and Health Officer</i> managed and led a team of <i>6 freelance</i> artists. Planning meetings were held with each artist and, where logistically possible, the artists met with <i>community representatives</i> to share their ideas for the creative delivery  Before the workshops began the artists, community representatives and interpreters supporting the sessions attended a training and briefing session led by the <i>Cancer Health Improvement Coordinator</i> No further information  Details below		information
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Before the workshops began the artists, community representatives and interpreters supporting the sessions attended a training and briefing session led by the Cancer Health Improvement Coordinator		
interpreters supporting the sessions attended a training and briefing session led by the Cancer Health Improvement Coordinator	,	
by the Cancer Health Improvement Coordinator		Details below
·		
Weekly workshops delivered between Sept-Dec 2010 5 workshops for	·	
	Weekly workshops delivered between Sept-Dec 2010	· ·
3hrs each to each		
community group		
A <b>documentation photographer</b> was contracted to attend each community  Details below	·	Details below
group to capture the different art activities, and provide high quality images		
which could be included in the resources and the documentation book for the project		
Graphic designers were commissioned to help turn the ideas and art work  Details below		Details below



	T
generated through the arts workshops into designs for the cancer awareness	
resources and consultations around these resources were delivered over 3	
phases	
Following the consultation, further changes to the translated text in all three	Details below
languages were made by the translation team and the graphic designers. The	
final finished resources were then proof read by key community representatives	
Lunches	5 workshops
In these workshops art pieces were created, many of which provided images and	words which were
used to inform the content and design of the cancer awareness resources. These se	essions also included
a social element, often over lunch, which provided an important opportunity for p	articipants to bond
and share their stories	
Phase 3: Identifying the outcomes	
The CAM survey was completed with 59 participants (pre and post survey)	No further
	information
Audio CD in Urdu and Punjabi provided by Dudley PCT to listen to at home	No further
	information
z-cards and fridge magnets were produced	Details below
A project documentation book was produced to capture the key images,	No further
messages and story of the project	information
Phase 4: Sharing and celebrating	
A celebration event at "The Venue" Dudley (June 15 <sup>th</sup> )	
Dudley PCT showcased the 'Life is Precious' project work at the Dudley 'Art	No further
<b>Space,</b> a new arts venue bringing free workshops and exhibitions for adults and	information
families into the heart of Brierley Hill town centre	
Phase 5: Building a legacy	
Overall <b>80 community members</b> were involved in the initial consultation	No further
meetings to discuss the role of Community Health Champions, 7 initial training	information
sessions were delivered, and 72 people have taken part in the Community	
Health Champions training sessions	
The Volunteer Coordinator has arranged 15 meetings and visits to Community	No further
Health Champions groups to support them to develop in this role, and 52	information
Community Health Champion badges were awarded at the Life is Precious	
Celebration Event, to those who have attended at least 2 Community Health	
Champion sessions	
54 Community Health Champions recruited	•

As the project was divided into five phases, the costs per phase were broken down to make the calculations more explicit. The following sections present the costs per phase. These have been estimated by Optimity, wherever possible using information provided in the evaluation report. Where the evaluation report has not provided relevant information on staff costs, Optimity Advisors have made illustrative assumptions about the resources required. Standard sources have been used for unit costs to generate monetary values. A summary of total costs by phase is given in Table 13 below the tables setting out the detailed costings for each phase.



Phase 1 costs (estimated using information on inputs from Curno et al., 2012 and Optimity assumptions)

Table 4: Resources for phase 1<sup>26</sup>

Input	Value from	Assumptions			Value	
	the report	Person	Cost/hr*	Rate		
		hours				
		Staff				
Representatives from	No further	32	£12.48	Local	£399	
Dudley PCT and Walsall	information			government		
Creative Development				administrative		
Team				occupations		
Community	No further	10	£7.30	Other	£73	
representatives	information			elementary		
				services		
				occupations		
				(not elsewhere		
				classified)		
Organisations from	No further	32	£15.03	Officers of	£481	
across the Dudley	information			non-		
borough				governmental		
				organisations		
Other resources						
Room and catering	No further	NA	NA	Assumed at no	NA	
	information			additional cost		
Total resource costs for	Total resource costs for phase 1					

<sup>\*</sup>Mean hourly pay, Gross

Phase 2 costs (estimated using information on inputs from Curno et al., 2012 and Optimity assumptions)

Table 5: Workshop resource cost<sup>27</sup>

Table 3. Workshop resource cost		
Staff per workshop as per Curno et al., 2012	Cost/hr*	Hrs of activity
Workshop 1		
Principal Arts in Health Development Officer	£19.65	3
Cancer Health Improvement Coordinator (CHIC)**	£11.02	1.5
DJS Research*** Interviewer 1 (Market research interviewers)	£9.05	1.5
DJS Research*** Interviewer 2 (Market research interviewers)	£9.05	1.5

<sup>&</sup>lt;sup>26</sup>Office for National Statistics, 2014. ASHE. Table 14.5 – Occupation. <a href="http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-337425">http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-337425</a>

<sup>&</sup>lt;sup>27</sup>Office for National Statistics, 2014. ASHE. Table 14.5 – Occupation. <a href="http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-337425">http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-337425</a>



Centre Coordinator (assumed same as CHIC)	£11.02	1.5
Artist	£13.70	1.5
Total cost of workshop 1 – staff only	£140	2.0
Workshop 2		
Healthy Communities Volunteer Coordinator	£11.02	3
Interpreter	£16.44	1.5
Centre Coordinator	£11.02	1.5
Artist	£13.70	1.5
Total cost of workshop 2 – staff only	£95	
Workshop 3		
Healthy Communities Volunteer Coordinator	£11.02	3
Interpreter	£16.44	1.5
Centre Coordinator (assumed same as CHIC)**	£11.02	1.5
Artist	£13.70	1.5
Documentary photographer	£13.60	1
Total cost of workshop 3 – staff only	£108	
Workshop 4		
Healthy Communities Volunteer Coordinator (assumed same as CHIC)	£11.02	3
Interpreter	£16.44	1.5
Principal Arts in Health Development Officer	£19.65	3
Cancer Health Improvement Coordinator (CHIC)**	£11.02	1.5
Documentary photographer	£13.60	1
Graphic designer	£13.69	1
Artist 1	£13.70	1.5
Artist 2	£13.70	1.5
Total cost of workshop 4 – staff only	£202	
Workshop 5		
Principal Arts in Health Development Officer	£19.65	3
Cancer Health Improvement Coordinator (CHIC)**	£11.02	2
Centre Coordinator (assumed same as CHIC)	£11.02	1.5
Interpreter	£16.44	1.5
Artists	£13.70	1.5
Documentary photographer	£13.60	1
Graphic designer	£13.69	1
DJS Research*** Interviewer 1 (Market research interviewers)	£9.05	1.5
DJS Research*** Interviewer 2 (Market research interviewers)	£9.05	1.5
Total cost of workshop 5 – staff only	£197	
Additional cost of graphic designers over 5 workshops per	£110 (assumed 8hrs at a cost of	
community group	£13.69 per hou	ir)
Total cost of 5 workshops per community group (sum of 5	£851	
workshops and additional graphic designer cost)	6470	
Average cost of workshop – staff only £170		
Total cost of 5 workshops for all community groups (6 groups)	£5,107	



# Cost per participant

£48.18

**Table 6: Other costs of workshops** 

Input	Notes	Value
Room hire – per workshop (VAT not	Assumed 25 people per	£138 <sup>28</sup>
specified, assumed that the rate is	room (staff and	
included in the price)	participants)	£690
Room hire per community group (5 workshops)	Based on £138 per room	1090
Total room hire for 6 community	Based on £690 per	£3,450
groups for 5 workshops	community group	
Supplies per person	Based on average price	£10
	www.Amazon.co.uk	
Supplies for all participants	Based on 106 participants	£1,060
Lunch per person	Working lunch menu excl.	£6.65 <sup>29</sup>
	VAT	
Lunch per person	Including 20% VAT	£7.98
No. of people in 5 workshops in 6	Includes number of staff	298
community group	and participants	
Total cost of lunch for workshops	At cost £7.98	£2,378

Phase 3 costs (estimated using information on inputs from Curno et al., 2012 and Optimity assumptions)

Table 7: Resources for phase 3<sup>30</sup>

Input	Value from	Assumption	Assumptions		
	the report	Man	Cost/hr*	Rate	
		hours			
		Staff			
Administration of the CAM survey, SWEMWBS and other tools	No further information	64	£11.02	Medical secretaries (CHIC)	£705
Production of the audio CD in Urdu and Punjabi	No further information	64	£13.82	Average rate of CHIC and interpreter	£884

 $<sup>^{28} \ \</sup>text{Premier Meetings. Premier Meetings London Euston.} \ \underline{\text{https://www.premiermeetings.co.uk/venue/london-euston/10}} \ [\text{Accessed 13/04/2015}]$ 

<sup>\*</sup>Mean hourly pay, Gross

<sup>\*\*</sup>Assumed medical secretaries

<sup>\*\*\*</sup>A market research company

<sup>&</sup>lt;sup>29</sup> Premier Meetings. Meeting Room Working Lunch Sandwich Selection. <a href="https://www.premiermeetings.co.uk/catering">https://www.premiermeetings.co.uk/catering</a> [Accessed 13/04/2015]

 $<sup>\</sup>frac{30}{O} Of fice for National Statistics, 2014. A SHE. Table 14.5 - Occupation. \\ \underline{http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-337425}$ 



CD production	No further information	NA	NA	NA	£510 (see Error! Reference source not found. for details)
Production of z-cards and fridge magnets	No further information	NA	NA	NA	£366 (see Error! Reference source not found Error! Reference source not found. for details)
A project documentation book	No further information	80	£11.02	Medical secretaries (CHIC)	£882
		Other resou	irces		
Room and catering	No further information	NA	NA	Assumed at no additional cost	NA
Total resource costs for	phase 3				£2,981

<sup>\*</sup> Mean hourly pay, Gross

# Table 8: Cost of fridge magnets (VAT exempt)

Input	Cost per unit <sup>31</sup>	Units	Total cost	Notes
Fridge magnets	£0.070	5,000	£351.50	We have made an assumption
(40*50mm)	£0.148	1,000	£148.00	about the type and number of
	£0.246	500	£123.00	fridge magnets

# Table9: Cost of z-cards (VAT exempt)

Input	Cost per unit <sup>32</sup>	Units	Total cost	Notes
Booklet (8 pages)	£0.137	5,000	£685.00	Cost assumed to be equal to
	£0.236	1,000	£236.00	cost of z-cards
	£0.364	500	£182.00	

It is assumed that in total 500 fridge magnets and 500 z-cards were produced following the workshops of 6 community group at a cost of £305 exclusive of VAT (phase 3).

Table 10: Total cost of fridge magnets and z-cards

0 0		
Toward	Maka	Malica
Input	Note	Value

<sup>&</sup>lt;sup>31</sup>My Fridge Magnets: <u>http://www.myfridgemagnets.co.uk/promotional-fridge-magnets-c6</u> (Accessed 23/12/2014)

 $<sup>{}^{32}</sup>Print\ Express:\ \underline{http://www.printexpress.co.uk/colour-printing/booklets/42/2p-n-032/}\ (Accessed\ 23/12/2014)$ 



Fridge magnets and z-cards	See Error! Reference source not found. & Error! Reference source not found.	£366 (inclusive of 20% VAT)
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# Table 11: CD production

Input	No. of units	Cost	Source
CD replication	500	£425 (excl.	http://www.pure-music.co.uk/cd-replication-
		VAT)	short-run/ [Accessed 13/04/2015]
CD replication	500	£510 (incl.	Calculation
		20% VAT)	

Phase 4 costs (estimated using information on inputs from Curno et al., 2012 and Optimity assumptions)

Table 12: Resources for phase 4

Table 12. Resources for	priase +			
Input	Value from	Assumption	Cost	Source
	the report			
A celebration event at	No further	Assumed to	£3,000	http://www.t-
"The Venue" Dudley	information	be attended		venue.com/index.php
		by 150		[Accessed 13/04/2015]
		people at a		
		cost of £20		
		per head		
Life is Precious'	No further	NA	Assumed at no	NA
project work at Dudley	information		additional	
'Art Space'			information	
Total cost for phase 4				£3,000

# Phase 5 costs

The average cost per Community Health Champion is assumed at £2,700 $^{33}$ . The project recruited 54 Community Health Champions (total cost of £145,800).

Table 13: Estimated total cost of *Life is Precious* 

Input
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 $\frac{\text{http://www.nice.org.uk/proxy/?sourceurl=http://www.nice.org.uk/usingguidance/sharedlearningimplementingniceguidance/examplesofimplem}{\text{entation/eximpresults.jsp?o=685}} \ [\text{Accessed 14/04/2015}]$ 

 $<sup>^{\</sup>rm 33}{\rm NICE}.$  Shared learning database.



Phase 1 (estimated using information on inputs from Curno et al., 2012 and	£953
Optimity assumptions)	
Phase 2 (estimated using information on inputs from Curno et al., 2012 and	£10,935
Optimity assumptions)	
Phase 3 (estimated using information on inputs from Curno et al., 2012 and	£2,981
Optimity assumptions)	
Phase 4	£3,000
Total of 4 phases for all participants (Life is Precious)	£17,870
Total of 4 phases per participant	£169
Phase 5 (Community Health Champions) – based on the NICE shared learning	£145,800
database	
Total of 5 phases for all participants	£163,670
Total of 5 phases per participant (106 participants of Life is Precious)	£1,544

# Connected Communities (C2) – Positively Local

#### Collaboration

#### **Project description**

Connecting Communities (C2) aims to generate pride in the community and is based on a theory of cocreation between residents and agencies. "The C2 model is a process of neighbourhood development that supports people in disadvantaged areas to champion their own agendas in partnership with agencies" (Gillespie et al., 2011) <sup>34</sup>. It is argued that development by statutory agencies of positive relationships with residents is a key to real and lasting neighbourhood change. The programme was implemented in three areas: Dartmouth, Townstal estate; Falmouth, Beacon estate and Cornwall, Redruth estate.

# **Project delivery**

C2 consists of seven steps. We summarise these steps below.

**Step 1**: Locate energy for change; it is important for those within or external to a given community who are concerned with mobilising the resources of the community and statutory agencies to effect change to identify the key residents with a commitment towards change. "These are not usually existing community activists. Existing activists often don't represent their neighbours and can even become obstacles to change" (Gillespie et al., 2011). It is also important to identify stakeholders from key agencies and include representatives from health, education, police and the local authority. In Townstal, the C2 process started with scoping visits to local Police and Communities Together (PACT) and town

<sup>&</sup>lt;sup>34</sup>Gillespie J, Hughes S, Duffy S, Glasby J, Needham C., 2011. Positively Local; C2 a model for community. University of Birmingham; Policy Paper 09.08.2011



council meetings. Key residents were identified at these meetings and further scoping visits made to using their local knowledge of community groups.

**Step 2**: Create vision; it is important to "set out not to do too much, so as not to raise people's hopes" (Gillespie et al., 2011) and release capacity to create an environment for change. The vision could come from outside the community in question and can be supported by organisations such as the Health Empowerment Leverage Project (HELP) to raise the ambitions of the community for change. The notion of capacity building in communities where capacity is regarded as insufficient can be counterproductive in the sense that communities are viewed as disempowered. Rather, capacity release can be enabled by statutory agencies listening to communities.

**Step 3**: Listening to communities; it is important for statutory agencies and service providers to capture the concerns and issues of the community. In Townstal, a connecting workshop held at the local Children's Centre was attended by 18 representatives from Education, Police, Devon PCT, Housing, South Hams District Council, local councillors and the Children's Centre and three key residents. A listening event, where priorities for the community were established, was attended by over 50 residents and facilitated by 18 local service providers.

**Step 4**: Formalise the partnership; this allows the neighbourhood to apply for funding. The Townstal Community Partnership was established as a resident-led, multi-agency partnership and the first meeting was held in July 2009. Partners included Devon County Council, Housing Associations, Devon and Cornwall Police, head teachers, local councillors, other local community organisations and groups and local businesses.

**Step 5**: Sustain momentum; this step is crucial to consolidate "...forces into something capable of bringing about widespread and long-standing change" (Gillespie et al., 2011). In Townstal, it is reported that, once the public meetings had started and word had spread, more residents began to attend the meetings to tell the services what was happening and where improvements were required.

**Step 6**: Taking action; this is the stage where the actions which aim to have a long-term benefit should be undertaken. In Townstal, changes on small issues like litter bins, resident support for the Partnership grew and residents and agencies understood that they had a forum where they could make change happen.

**Step 7**: Continued trajectory of improvement; it is important to maintain and enhance improved changes. When it snowed in early 2010, residents came to the meeting of the Partnership to complain about the lack of provision for grit bins. As a result, the Highways' representative was contacted and it was agreed that Townstal would receive more grit bins.

**Project outcomes** 



As noted above the project was implemented in three areas in the UK – Dartmouth, Falmouth and Cornwall. Some of the outcomes reported by the project evaluation are summarised below. The reported changes are identified as improvements for the estate in question. For example, the evaluation report states that the Beacon estate experienced "improvements in health, environment and educational outcomes between 1995 and 2000"

#### Health outcomes;

In Falmouth (Beacon estate), it was reported that, following the programme, a number of health indicators improved on the estate (although figures are not reported for the situation before as compared with after the programme). For example, it was reported that breast feeding rates have risen and postnatal depression rates fallen. In addition there was a decrease identified in the (overall) childhood accident rate and the provision of on site health advice at the health centre was cited as an example of an improvement in health outcomes. Further details are presented in the table of findings.

#### Environmental outcomes;

There were some positive environmental outcomes on the Beacon estate following the C2 programme, such as an increase in loft insulation (349 properties), central gas heating installation (318 properties) and fuel saving estimated at £180,306. In addition, recycling increased, dog waste bins were installed and a Skateboard Park developed (all Beacon estate). Further details are presented in the table of findings.

# Educational outcomes;

The programme provided on-site training for tenants and residents. After school club, skills course and parent and toddler groups (Beacon estate) were identified as representing improvements in educational outcomes (although their activities have not been quantified). Further details are presented in the CCA section.

# Additional outcomes.

The report presents decrease in fear of crime, as well as reduced crime and a decrease in unemployment. On the Townstal estate, for the first time, there was a dentist on the estate (one day a week). The Redruth estate developed a voluntary curfew.

# Aspect of community engagement:

The project is a process of neighbourhood development and supports people in disadvantaged areas.

## Type of community engagement - Collaboration:



This project was classified in this category due to the following characteristics: "The C2 model is a process of neighbourhood development that supports people in disadvantaged areas to champion their own agendas in partnership with agencies" <sup>35</sup>.

# **Key findings**

The table below presents key findings from the cost-consequence analysis, including a short description of the intervention, study outcomes as reported directly in the text (whereby green indicates a positive outcome; amber no difference or a non-statistically significant finding; and red indicates a negative outcome), as well as a description of consequences, and any financial consequences that could be calculated.

Table 14: Key findings

Table 14: Key findir	ıgs
Intervention	Gillespie J, Hughes S, Duffy S, Glasby J, Needham C., 2011. Positively Local; C2 a
paper	model for community. University of Birmingham; Policy Paper 09.08.2011
Intervention	Connecting Communities (C2) – Positively Local
Study design	Case study
	Theoretical approach: collaboration
	Conducted in the UK
	<ul> <li>Dartmouth, Townstal estate;</li> </ul>
	<ul> <li>Falmouth, Beacon estate;</li> </ul>
	<ul> <li>Cornwall, Redruth estate.</li> </ul>
	Follow-up: 3-5 years (Beacon estate)
Intervention	The C2 model is a process of neighbourhood development that supports people
description	in disadvantaged areas to champion their own agendas in partnership with
	agencies. This case study is based on the premise that developing positive
	relationships with residents is the best way to effect real and lasting
	neighbourhood change.
Intervention cost	The average cost of a similar programme, the Health Empowerment Leverage
	Project (HELP), that adopted the C2 method, was estimated at £72,750 per year
	or ca. £15/person (2011 prices) <sup>36</sup> . Despite the name, HELP can be regarded as a
	collaborative project. Positively Local was chosen for this cost consequence
	analysis because it was the subject of a case study undertaken to inform the
	development of the guideline on community engagement. In addition, the
	Positively Local report discusses the Townstal site to which the HELP report
	specifically refers and presents a fuller set of consequences than the HELP

<sup>&</sup>lt;sup>35</sup>Gillespie J, Hughes S, Duffy S, Glasby J, Needham C., 2011. Positively Local; C2 a model for community. University of Birmingham; Policy Paper 09.08.2011

<sup>&</sup>lt;sup>36</sup>Fisher B, Stuteley H, Chanan G, Hughes S, Miller C, Griffiths G. 2011. Empowering Communities for Health: Business Case and Practice Framework. 1-101 <a href="http://www.healthempowerment.co.uk/wp-content/uploads/2012/11/DH">http://www.healthempowerment.co.uk/wp-content/uploads/2012/11/DH</a> report Nov 2011.pdf



	report.				
Study outcomes	Health outcomes (Beacon estate) as recorded in the evaluation report				
(as per Gillespie	Increase in breast feeding rates by 50%				
et al. 2011) –	Postnatal depression rates down by 70%				
reported without	Childhood accident rate down by 50%				
attribution	Reduced fear of crime				
	Health centre providing on site health advice				
	Sexual health service for young people				
	Teenage pregnancy dropped to zero in 2004				
	Unemployment dropped by 71%				
	Environmental outcomes (Beacon estate)				
	£2.2million granted by tenants and residents				
	Gas central heating to 318 properties				
	Loft insulation in 349 properties				
	Fuel saving estimated at £180,306				
	£160,000 traffic calming measures				
	Provision of safe play areas				
	Recycling and dog waste bins				
	Skateboard park				
	Educational outcomes (Beacon estate)				
	On-site training for tenants and residents				
	After school clubs				
	Life skills courses				
	Parent and toddler group				
	100% improvement in boys SATS results				
	IT skills				
	Crèche supervisor training				
	Other outcomes (Townstal estate)				
	Crime fell within the first year of the partnerships (although a quantified				
	estimate was not reported in Positively Local)				
	Additional £45k generation towards refurbishment of a park; involved the school				
	and local children in redesigning the park				
	Lessons about community (sense of community)				
	Services offering counselling, advice on housing etc. to young people				
	New security entrances				
	Litter pick days				
	Employment of two caretakers to help with maintenance				
	For the first time, an NHS dentist on estate once a week				
	Pioneering voluntary curfew (Redruth estate)				
Financial	As per Gillespie et al. (2011), it was suggested that postnatal depression has				



# consequences

decreased following the implementation of C2. However, the implications of a decrease in postnatal depression in terms of cost-savings are not presented. Therefore, here we present some potential financial consequences of this change. One study has reported that, for a mother-infant dyad (two individuals or units regarded as a pair<sup>37</sup>), the cost difference between mothers with and without post-natal depression was ~£527 (P=0.17)<sup>38</sup> [2013 costs] meaning that health and social care costs for mother with post-natal depression were higher by around £527 compared to mother without the condition.

Petrou et al. 2002 report that a decrease in post-natal depression results in changes in health care resource use. The mean difference in health care service use between mothers with and without post-natal depression is presented below. The positive numbers mean that more services were used by <a href="mailto:mothers">mothers</a> without post-natal depression. The negative numbers mean that fewer services were used by <a href="mailto:mothers">mothers</a> without post-natal depression

Resource	Difference	Unit cost [2013	
	between	costs]	
	service use		
Mother: community care services			
Midwifery contacts	0.3	£25/hr	
GP contacts	-2.37	£37 (11.7min <sup>39</sup> )	
Practice nurse contacts	-0.15	£24/hr	
Practice counsellor contacts	-0.47	£28/hr	
Health visitor contacts	0.31	£77/hr	
Home help contacts	0.04	£14/hr	
Social worker contacts	-1.76	£31/hr	
Physiotherapist contacts	-0.85	£46/hr	
Community psychiatric nurse contacts	-1.74	£75/hr	
Community psychologist contacts	-0.62	£82/hr	
Other community mental health	-0.23	£79/hr	
contacts			
Other community care contacts	-0.87	£54/hr	
Mother: day care services			
Day hospital attendances	No difference	£28/attendance	
Community based day care attendances	0.13	£23/attendance	
Other day care attendances	0.08	£23/attendance	
Mother: hospital outpatient admissions			

 $<sup>^{37}</sup> The \ Free \ Dictionary. \ \underline{http://www.thefree dictionary.com/dyad} \ [Accessed 19/06/2015]$ 

<sup>&</sup>lt;sup>38</sup>Petrou S, Cooper P, Murray L, Davidson LL. 2002. Economic costs of post-natal depression in a high-risk British cohort. British Journal of Psychiatry; 181: 505-512

<sup>&</sup>lt;sup>39</sup>PSSRU, 2013. <a href="http://www.pagb.co.uk/media/facts.html">http://www.pagb.co.uk/media/facts.html</a>



Obstetric care attendances	-0.02	£70/attendance	
A&E emergency care attendances	0.04	£81/attendance	
Other outpatient attendances	-0.3	£237/attendance	
Mother: hospital inpatient admissions (days)			
Maternity ward admissions	-0.26	£213/day	
Mother & baby unit admissions	-0.1	£213/day	
Medical/surgical ward admissions	0.04	£245/day	
Other hospital inpatient admissions	0.02	£317/day	
Infant: paediatric & child care services			
Day nursery attendances	-1.13	£27/attendance	
GP contacts	-1.5	£37 (11.7min <sup>40</sup> )	
Community paediatrician contacts	0.01	£130/contact	
Hospital paediatrician contacts	0.15	£130/contact	
A&E care attendances	-0.2	£81/attendance	
Special care baby unit admissions	-0.11	£737/day	
Paediatric ward admissions	0.17	£374/day	
Physiotherapist contact	0.19	£46/hr	
Other paediatric & child care contacts	0.35	£63/hr	

It was also reported by Gillespie at al. (2011) that childhood accident rates decreased, but no figures were reported. Therefore, here we present childhood accident care costs that can be potentially ameliorated by C2 programme. In the literature, the accident cost is reported to be between £65 (No Investigation with No Significant Treatment) to £342 (Any Investigation with Category 5 Treatment)<sup>41</sup>.

Gillespie et al. also report that the crime fell within the estate. However, the fall rate/level or change or nature of the crime is not presented, therefore it is not possible to calculate the potential benefits of crime decrease in monetary terms. However, here we present average cost of crime to illustrate the potential benefits of C2<sup>42</sup>:

- Violence against the person £19,000;
- Wounding (serious and slight) £18,000;
- Common assault £540;
- Sexual offences £19,000;
- Robbery/mugging £4,700;

https://www.gov.uk/government/uploads/system/uploads/attachment data/file/191497/Green book supplementary guidance economic social costs of crime.pdf

<sup>&</sup>lt;sup>40</sup>PSSRU, 2013. <a href="http://www.pagb.co.uk/media/facts.html">http://www.pagb.co.uk/media/facts.html</a>

 $<sup>^{41} \</sup>text{NHS Reference cost 2012-13.} \ \underline{\text{https://www.gov.uk/government/publications/nhs-reference-costs-2012-to-2013}}$ 

<sup>&</sup>lt;sup>42</sup>Brand S, Price R., 2000. Home Office Research Study 2017. The economic and social costs of crime.



	Burglary in a dwelling - £2,300;	
	Theft (not vehicle) - £340;	
	Theft (of vehicle) - £890;	
	Criminal damage - £510.	
	It is also reported by Gillespie et al. (2011) that unemployment fell. The benefit of this could potentially be converted into increased production for the	
	(unspecified) number no longer unemployed.	
Descriptive	As noted before, following the implementation of C2, breastfeeding rates are	
consequences	reported to have increased. Breastfeeding has a number of potential benefits	
	and here we present further potential outcomes of breastfeeding:	
	<ul> <li>Type 2 diabetes: a WHO met-analysis concluded that breastfeeding may have a protective effect against type 2 diabetes<sup>43</sup>;</li> </ul>	
	Overweight-obesity: the WHO meta-analysis estimated a 10% decrease in	
	overweight or obesity in children exposed to longer durations of breastfeeding;	
	<ul> <li>Intelligence test: the WHO meta-analysis suggested that breastfeeding is associated with improved performance in intelligence tests in childhood and adolescence.</li> </ul>	

# **Leeds Gypsy and Traveller Exchange (GATE)**

# **Empowerment**

# **Project description**

The Leeds Gypsy and Traveller Exchange (GATE) programme aims to improve the lives of Gypsies and Travellers in Leeds and West Yorkshire. GATE is a membership organisation although no fees are charged to the members of the Gypsy and Traveller communities it represents. The organisation was started by Gypsy and Irish Traveller people working with friends and colleagues from other communities to improve the quality of life of their families and communities <sup>44</sup>. It has received funding from organisations such as the Joseph Rowntree Charitable Trust and Comic Relief, GATE has recruited staff who have worked with members on projects such as the West Yorkshire Gypsy and Traveller Accommodation Needs Assessment and a National Gypsy Health and Inclusion project which was jointly led by GATE and Friends Family and Travellers.

http://apps.who.int/iris/bitstream/10665/79198/1/9789241505307\_eng.pdf

 $<sup>^{43}</sup>$ Horta BL, Victora CG. 2013. Long-term effects of breastfeeding; A systematic review. The World Health Organization.

<sup>44</sup> http://www.leedsgate.co.uk/home/about-leeds-gate/a-history-of-leeds-gate/



GATE undertakes frequent consultations and most of the members of its Executive Board are drawn from the Gypsy and Traveller community. GATE provides personal support and advocacy, including help with housing health needs and education and training. GATE has four main objectives:

- Accommodation provision;
- Improve health and wellbeing;
- Improve education, employment and financial inclusion;
- Increase citizenship and social inclusion.

In addition, GATE aims to achieve wider societal benefits for these communities. Staff recruited by GATE, such as an advocacy worker and youth inclusion co-ordinator work with Gypsies and Travellers, providing personal support, advocacy and representation to mainstream services . GATE also helps to raise awareness and knowledge about these communities. GATE's advocacy worker is sometimes supported by students on placement. While GATE workers are not necessarily part of the Gypsy and Traveller community, 75% of GATE's management committee members are Gypsies and Travellers<sup>45</sup>. GATE aims "...to help Gypsies and Travellers help themselves, through building the community's capacity, skills and capabilities" (Bagley, 2014)<sup>46</sup>.

#### **Project delivery**

The project work involves GATE staff and others (such as placement students) in providing advocacy and support services for Gypsies and Travellers. For example, GATE has agreed a negotiated stopping arrangement by which it is agreed with the local authorities that Gypsies and Travellers can remain at specified sites for a period of time. GATE helps with accommodation by liaising with local authorities on behalf of Travellers on access to funding, for example to enable adaptations to caravans for those in failing physical and mental health, and helps engagement with NHS services, for example by accompanying people to important appointments. Leeds GATE also represents Gypsies and Travellers at national forums led by the Department of Health, NHS England and the Department for Communities AND Local Government.

# **Project outcomes**

GATE has four key areas of activity, with examples of some of the benefits identified in the evaluation report (Bagley, 2014) summarised below.

## 1. Improve accommodation;

GATE helped the community to liaise on funding for disabled facilities grants that allow disabled facilities to be developed (adaptations and extensions to caravans). In turn, this development allows disabled and elderly residents of gypsy and traveller sites to continue living at home and reduces the need for relocation. In addition, GATE helps to improve living conditions by providing advocacy and helping

 $<sup>^{45}</sup>$  The Leeds GATE team is given at http://www.leedsgate.co.uk/home/the-leeds-gate-team/

<sup>&</sup>lt;sup>46</sup>Bagley A. 2014. Leeds Gate; Gypsy and Traveller Exchange. Service Evaluation Report



caravans to stay on the site permanently or temporarily. This in turn helps to avoid evictions and save eviction costs (Bagley, 2014).

#### 2. Improve health;

GATE helps communities to engage with national health services. It was reported that GATE helped to get NHS podiatrist and palliative care visits to the site, as well as midwife visits to expectant mothers. It is also claimed, in the evaluation report, that the take up of immunisation generally has increased and that the initiative has helped Gypsies and Travellers to understand the importance of HPV vaccination. More details on health benefits are presented in the cost-consequence analysis section (Bagley, 2014).

# 3. Improve education and employment;

GATE helped to improve educational attainment for young people within the community and increase children's confidence and learning. The programme also delivered healthy eating and cooking courses. Further details on education and employment benefits are presented in the cost-consequence analysis section.

#### 4. Social inclusion;

In partnership with other organisations, GATE helps to raise awareness and promote the inclusion of these communities into society. Further details on social inclusion benefits are presented in the cost-consequence analysis section.

## Aspect of community engagement:

The project is aiming to improve quality of life of Gypsy and Traveller communities.

# Type of community engagement – Empowerment:

This project was classified in this category due to the following characteristic: the majority of GATE's executive board are gypsies and travellers, in line with the concept of empowerment that the community has a lead role in designing the intervention.

# **Key findings**

The table below presents key findings from the cost-consequence analysis, including a short description of the intervention, study outcomes as reported directly in the text (whereby green indicates a positive outcome; amber no difference or a non-statistically significant finding; and red indicates a negative outcome), as well as a description of consequences, and any financial consequences that could be calculated. As discussed above, outcomes in this example were all positive and so were shaded green as with the other case studies.

More detail on how these results were calculated is shown below this table.

N.B. The report by Bagley 2014 presents an evaluation of the GATE services. As a method for evaluation a number of tools were used. The evaluation presents the information from "...desktop analysis (from



GATE's own reports and also external papers), discussions with staff and board members, including Gypsy and Traveller representatives, and interviews with third parties, conducted by telephone" <sup>47</sup>. No information on measurement scales or surveys used are presented.

Table 15: Key findings

Table 15: Key finding		
Intervention	Bagley A. 2014. Leeds Gate; Gypsy and Traveller Exchange. Service Evaluation	
paper	Report	
Intervention	Leeds Gypsy and Traveller Exchange (GATE). GATE is a membership organisation whose Executive Board has majority membership from gypsies and travellers.	
Study design	Case study	
, 0	Theoretical approach: empowerment	
	Conducted in the UK	
	<ul> <li>Leeds and West Yorkshire</li> </ul>	
Intervention	GATE aims to improve the quality of life of people in Gypsy and Traveller	
description	communities.	
	The key objectives include:	
	Improving accommodation provision;	
	2. Improving health and well-being;	
	3. Improving education, employment and financial inclusion;	
	4. Increasing citizenship and social inclusion.	
Intervention cost	Cost per advocacy case* dealt with by GATE is £122. The figure is reported by Real-Improvement 2015 report <sup>48</sup> . The definition of advocacy case is presented at	
	the end of this table	
Study outcomes	the end of this table  Accommodation	
Study outcomes	Accommodation	
as per Bagley	Accommodation  The interventions have been associated with impacts on a wide range of	
-	Accommodation  The interventions have been associated with impacts on a wide range of stakeholders, including:	
as per Bagley	Accommodation  The interventions have been associated with impacts on a wide range of stakeholders, including:  Gypsy and Traveller families;	
as per Bagley	Accommodation  The interventions have been associated with impacts on a wide range of stakeholders, including:  Gypsy and Traveller families;  Elderly residents in failing health and their families and friends;	
as per Bagley	Accommodation  The interventions have been associated with impacts on a wide range of stakeholders, including:  Gypsy and Traveller families;  Elderly residents in failing health and their families and friends;  Leeds City Council;	
as per Bagley	Accommodation  The interventions have been associated with impacts on a wide range of stakeholders, including:  Gypsy and Traveller families;  Elderly residents in failing health and their families and friends;  Leeds City Council;  Local Authority Social Services;	
as per Bagley	Accommodation  The interventions have been associated with impacts on a wide range of stakeholders, including:  Gypsy and Traveller families;  Elderly residents in failing health and their families and friends;  Leeds City Council;  Local Authority Social Services;  Police.	
as per Bagley	Accommodation  The interventions have been associated with impacts on a wide range of stakeholders, including:  Gypsy and Traveller families;  Elderly residents in failing health and their families and friends;  Leeds City Council;  Local Authority Social Services;  Police.  GATE helped to liaise on funding for Disabled Facilities Grants to adopt facilities	
as per Bagley	Accommodation  The interventions have been associated with impacts on a wide range of stakeholders, including:  Gypsy and Traveller families;  Elderly residents in failing health and their families and friends;  Leeds City Council;  Local Authority Social Services;  Police.  GATE helped to liaise on funding for Disabled Facilities Grants to adopt facilities for the disabled. The new facilities enabled residents to continue living at home.	
as per Bagley	Accommodation  The interventions have been associated with impacts on a wide range of stakeholders, including:  Gypsy and Traveller families;  Elderly residents in failing health and their families and friends;  Leeds City Council;  Local Authority Social Services;  Police.  GATE helped to liaise on funding for Disabled Facilities Grants to adopt facilities for the disabled. The new facilities enabled residents to continue living at home. It is thought that residents:	
as per Bagley	Accommodation  The interventions have been associated with impacts on a wide range of stakeholders, including:  Gypsy and Traveller families;  Elderly residents in failing health and their families and friends;  Leeds City Council;  Local Authority Social Services;  Police.  GATE helped to liaise on funding for Disabled Facilities Grants to adopt facilities for the disabled. The new facilities enabled residents to continue living at home.	

 $<sup>^{</sup>m 47}$ Bagley A. 2014. Leeds Gate; Gypsy and Traveller Exchange. Service Evaluation Report

 $<sup>^{\</sup>rm 48}$  Real-Improvement. 2015. Leeds GATE. Advocacy Service Evaluation Report

 $<sup>^{\</sup>rm 49} \textsc{Bagley}$  A. 2014. Leeds Gate; Gypsy and Traveller Exchange. Service Evaluation Report



The programme can help to avoid the high costs of residential and/or nursing homes.

GATE advocated "Negotiated Stopping" that allows temporary residence on the site until the caravan is offered a permanent site or moves on. As a result:

- Living conditions have improved;
- Access to healthcare and education/training has improved;
- Evictions have been avoided. "Eviction and clean-up costs, quoted as £2m between 2003 and 2010, greatly reduced"50;
- There were reduced issues due to unmanaged camps;
- Enables police to direct residents to established sites.

#### Health

The interventions benefits a wider range of stakeholders, including:

- Patients and their families;
- Wider Gypsy and Traveller communities;
- NHS and public health services;

The report claims that GATE helped with update and engagement with NHS services (no baseline data or a change in terms of numbers are presented):

- A midwife visits expectant mothers at the site;
- NHS podiatrist and palliative care visits to the site;
- Ad hoc health checks at the site;
- Immunisation take up has increased;
- Access to GP and secondary NHS services has improved according to the
  evaluation report, with GATE sometimes accompanying members on
  hospital visits, midwife visits to and health checks taking place at Cottingley
  Springs, and an increase in the take-up of immunisations;
- GATE played an important role in the development of Leeds Health Needs Assessment (Leeds health equalities strategy) according to the evaluation report and has published a Health Needs Assessment<sup>51</sup>;
- GATE is promoting community members to help others to understand and access the healthcare services.

According to the report by Bagley 2014, in particular:

- GATE helped patients to understand discharge arrangements and the importance of self-care;
- GATE helped patients' families to understand patients' health and support needs;

According to the report by Bagley 2014 GATE helped Gypsies and Travellers in

<sup>&</sup>lt;sup>50</sup>Bagley A (2014). Leeds GATE Service Evaluation Report. Leeds: Real-Improvement

 $<sup>^{51}</sup>$  Leeds Gypsy and Traveller Community Health Needs Assessment. Leeds: Leeds GATE.



Leeds to understand the importance of HPV vaccination for cervical cancer by bringing people to awareness sessions run by community health workers. This enabled:

- Lifetime protection against cervical cancer caused by HPV for those girls receiving the vaccination;
- Increased awareness of cancer risks and promotion of better uptake of services generally;
- NHS and public health services to achieve health objectives and potentially helped to reduce future cancer care needs.

# **Education & employment**

The interventions benefits a wider range of stakeholders, including:

- Children and their families;
- Schools:
- Leeds City Council;
- Wider Gypsy and Traveller communities in Leeds;
- NHS and public health services.

According to the report by Bagley 2014 GATE helped to improve attainment for young people. GATE helped parents to arrange access to education for their children who were bullied or poorly supported at school, In one case study of home schooling, the following benefits were identified in the evaluation report:

- Children's confidence and learning improved;
- There were reduced concerns about falling behind in education;
- GATE helped Leeds City Council to obtain statutory education for children at minimal cost;
- Reduced pressures from the need to control bullying and other potential conflicts (however, it could be argued that this also reduces diversity and understanding, helping to maintains the marginalisation of Gypsy and Traveller children).

GATE, in partnership with Leeds Health Living Network, helped to deliver health eating and cooking courses. The course aimed to educate young people on the impacts of a healthy diet:

- GATE helped better understanding of healthy eating;
- GATE increased knowledge and learning of healthy recipes;
- GATE aimed to generate peer encouragement of healthy eating among gypsies and travellers;
- Consequently better health for the community and reduced health care burden\*\*.

# **Social inclusion**

GATE aims to involve gypsies and travellers in social activities (e.g. elections).



The interventions benefits a wider range of stakeholders, including:

- gypsies and travellers;
- The general public.

GATE, in partnership with the Traveller Movement helped gypsies and travellers to make representations to the Council to reduce antipathy against their community. It is anticipated that GATE can reduce the fear of antagonism and harassment for gypsies and travellers and enhance better understanding of this community group (anticipated outcomes).

GATE is also trying to raise awareness nationally and promote the inclusion of gypsies and travellers into society.

GATE helped to obtain a portakabin for the community that holds various events. This gives the community a place to meet (however, at present the space is not well used).

# Financial consequences

#### Health

A report by Bagley (2013) presents an illustrative cost analysis of the way in which GATE services could facilitate improvements in health care for Gypsies and Travellers<sup>52</sup>. The analysis is performed to compare the costs of two alternative scenarios for the provision of care in dementia and bowel cancer. The scenarios are intended to provide examples of current practice versus improved practice that might be achieved through GATE services. "These scenarios are based on the real experience of Gypsy and Traveller families in this country. For each scenario there are two versions; the first is based on what currently tends to happen in practice; the second shows how this can be improved with greater knowledge and understanding on the part of health and social care professionals" (Bagley, 2013 p.3). The two scenarios are based on hypothetical depictions by the report's author of early interventions which, by recognising the cultural needs of Gypsies and Travellers, could potentially have benefits for the NHS. The assumptions around resource use and estimates of unit cost are set out in Bagley (2013).

Potential financial consequences are:

Dementia and Carer Stress/Depression

Pathway 1: Current Practice

Total financial cost: £20,298

Bowel Cancer

Pathway 2: Improved Practice

Total financial cost: £8,884

<sup>&</sup>lt;sup>52</sup>Bagley A. 2013. Leeds Gypsy and Traveller Exchange. "Gypsy and Traveller Health – Who pays?". Health Pathways: Cost-Benefits Analysis Report. Leeds: Leeds GATE. <a href="http://www.leedsgate.co.uk/wp-content/uploads/2013/06/Cost-Benefit-Analysis-report-Gypsy-and-Traveller-Health-Pathways.pdf">http://www.leedsgate.co.uk/wp-content/uploads/2013/06/Cost-Benefit-Analysis-report-Gypsy-and-Traveller-Health-Pathways.pdf</a>



	Pathway 1: Current Practice	Pathway 2: Improved Practice	
	Total financial cost: £ £22,956	Total financial cost: £4,058	
	Accommodation  Leeds City Council is estimated to be saving £200,000 per annum by implementing temporary sites for Gypsies and Travellers.  Leeds GATE is being promoting "negotiated stopping site". Leeds City Council estimated savings of £100,000 in clean-up costs <sup>53</sup> .		
Descriptive	Accommodation		
consequences	The programme can help to avoid the high cost of residential and/or nursing homes. It is estimated that the cost of residential care per annum is £28,500 (per person). If nursing care is necessary, the cost increases to £37,500 per year (per person). The cost of nursing varies by region and the UK average is estimated at £459 per week for residential care and £715 for nursing homes (per person) <sup>54</sup> .		
	Health  Immunisation take up has increased as a result of GATE work, widening access to commonly provided services (albeit implying an increased in demands on the NHS). Vaccination enables "a rich, multifaceted harvest for societies and nations. Vaccination makes good economic sense, and meets the need to care for the weakest members of societies" 55.  GATE helped Gypsies and Travellers in Leeds to understand the importance of HPV vaccination. Cervical cancer is the second most common cancer in women under age 35. A vaccine used in NHS services "protects against the two types of HPV that account for more than 70% of cervical cancers in the UK 56.		
	GATE helped with engagement with NHS services and midwife visits to expectant mothers at the site were arranged, widening access to commonly provided services (albeit implying an increased in demands on the NHS). This is particularly beneficial as Gypsies and Travellers experience 3 times higher infant mortality compared to the national average <sup>57</sup> .		
	Education & employment	es to education "Education can being	
	GATE helped parents to arrange acce	ss to education. "Education can bring	

<sup>&</sup>lt;sup>53</sup>Leeds Gypsy and Travellers Exchange; Financial Statements; 30 November 2013

<sup>&</sup>lt;sup>54</sup>Paying For Care. Care home fees. Data from LaingBuisson. 2014. Care of Older People; UK Market Report; Twenty-Sixth Edition. http://www.payingforcare.org/care-home-fees [Accessed 29/04/2015]

<sup>&</sup>lt;sup>55</sup>WHO. Andre FE, Booy R, Bock HL, Clemens J, Datta SK, John TJ, Lee BW, Lolekha S, Pelthola H, Ruff TA, Santosham M, Schmitt HJ. Bulleting of the World Health Organization. Vaccination greatly reduced disease, disability, death and inequality worldwide.

http://www.who.int/bulletin/volumes/86/2/07-040089/en/ [Accessed 29/04/2015]

<sup>&</sup>lt;sup>56</sup>NHS. NHS choices. HPV vaccine. <a href="http://www.nhs.uk/conditions/vaccinations/pages/hpv-human-papillomavirus-vaccine.aspx">http://www.nhs.uk/conditions/vaccinations/pages/hpv-human-papillomavirus-vaccine.aspx</a> [Accessed 29/04/2015]

<sup>&</sup>lt;sup>57</sup>Irish Traveller Movement in Britain. 2012. The Health and Wellbeing of Gypsies and Travellers. An Irish Traveller Movement in Britain Briefing. http://irishtraveller.org.uk/wp-content/uploads/2012/03/ITMB-Gypsy-and-Traveller-Health-Briefing-March-20122.pdf [Accessed 29/04/2015]



	significant benefits to society, not only through higher employment opportunities and income but also via enhanced skills, improved social status and access to networks" <sup>58</sup> . It has also been found that life expectancy is associated with education <sup>59</sup> . The latter is especially important taking into account Gypsies and Travellers' life expectancy compared to the UK average of 50 years and 78 years (Leeds) relatively <sup>60</sup> .  Social inclusion  It is found that Gypsies and Travellers experience issues in relation to aspects of health, education, employment, lack of access to facilities and their "culture and identity receive little or no recognition, with consequent and considerable damage to their self-esteem" <sup>61</sup> .
Additional	Financial security
consequences	Leeds GATE and the Irish Traveller Movement in Britain (ITMB) held roundtable
	discussions to address concerns regarding the introduction of Universal Credit (UC) <sup>62</sup> .

\*Advocacy is "...defined as speaking or writing in favour of, representing by argument or public recommendation..." <sup>63</sup> and is aiming at improving accommodation provision, improving health and wellbeing, improving education, employment and financial inclusion, and increasing citizenship and social inclusion. The corresponding cost per case delivered by Citizens Advice Bureau is estimated at £73; however, volunteers in the latter do not undertake home visits <sup>64</sup>. The Real-Improvement (2015) report estimates a cost per case dealt with by GATE's advocacy services of £122.

http://www.equalityhumanrights.com/sites/default/files/documents/research/12inequalities experienced by gypsy and traveller communities a review.pdf [Accessed 29/04/2015]

<sup>&</sup>lt;sup>58</sup>OECD. 2010. Education Indicators in Focus. <a href="http://www.oecd.org/education/skills-beyond-school/EDIF%202013--N%C2%B010%20%28eng%29-v9%20FINAL%20bis.pdf">http://www.oecd.org/education/skills-beyond-school/EDIF%202013--N%C2%B010%20%28eng%29-v9%20FINAL%20bis.pdf</a> [Accessed 29/04/2015]

<sup>&</sup>lt;sup>59</sup>OECD. 2010. Education Indicators in Focus. <a href="http://www.oecd.org/education/skills-beyond-school/EDIF%202013--N%C2%B010%20%28eng%29-v9%20FINAL%20bis.pdf">http://www.oecd.org/education/skills-beyond-school/EDIF%202013--N%C2%B010%20%28eng%29-v9%20FINAL%20bis.pdf</a> [Accessed 29/04/2015]

<sup>&</sup>lt;sup>60</sup>Irish Traveller Movement in Britain, Leeds Gate. 2013. Impact of universal credit and welfare reforms on the Gypsy and Traveller communities. A report by the Irish Traveller Movement in Britain and Leeds GATE. <a href="http://irishtraveller.org.uk/wp-content/uploads/2013/05/Universal-Credit-and-Gypsies-and-Travellers-report.pdf">http://irishtraveller.org.uk/wp-content/uploads/2013/05/Universal-Credit-and-Gypsies-and-Travellers-report.pdf</a> Data from: Baker, M., Leeds Racial Equality Council, 2005, Leeds Baseline Census 2004-2005, p. 10 <a href="http://www.grtleeds.co.uk/information/census.html">http://www.grtleeds.co.uk/information/census.html</a>

<sup>&</sup>lt;sup>61</sup>Cemlyn S, Greenfields M, Burnett S, Matthews Z, Whitwell C. 2009. Inequalities experienced by Gypsy and Traveller communities: A review. Research report: 12.

<sup>&</sup>lt;sup>62</sup>Irish Traveller Movement in Britain, Leeds Gate. 2013. Impact of universal credit and welfare reforms on the Gypsy and Traveller communities. A report by the Irish Traveller Movement in Britain and Leeds GATE. <a href="http://irishtraveller.org.uk/wp-content/uploads/2013/05/Universal-Credit-and-Gypsies-and-Travellers-report.pdf">http://irishtraveller.org.uk/wp-content/uploads/2013/05/Universal-Credit-and-Gypsies-and-Travellers-report.pdf</a>

 $<sup>^{63}</sup>$ Real-Improvement. 2015. Leeds GATE. Advocacy Service Evaluation Report. Page 2

<sup>&</sup>lt;sup>64</sup>Real-Improvement. 2015. Leeds GATE. Advocacy Service Evaluation Report



\*\*"NB: These outcome are based on feedback from participants at the end of the course. There is limited evidence of the extent to which these healthy cooking and eating practices are sustained or spread across the community"<sup>65</sup>.

 $<sup>^{65}\</sup>mbox{Bagley}$  A. 2014. Leeds Gate; Gypsy and Traveller Exchange. Service Evaluation Report



# 3. Conclusions

The three case studies reported here have reported a range of benefits, including health benefits, from interventions of relatively low intervention cost (albeit on the basis of retrospective estimates which may be incomplete in some aspects). Health effects reported range from improved cancer awareness and mental wellbeing (Life is Precious) to increased breastfeeding rates, reduced postnatal depression, reduced childhood accidents and fewer cases of asthma (Connecting Communities) to improved access to health services including increased uptake of interventions known to be cost effective (HPV vaccine – Leeds Gate). These impacts, together with intervention costs, could potentially be converted into QALYs and cost impacts to generate a cost-effectiveness ratio for which established benchmarks exist for judging whether an intervention is considered a good use of NHS funds (£20-30,000 per QALY gained). The findings of the Evaluation Reports, although they did not set out to investigate cost-effectiveness, suggest that these interventions could be cost-effective (or possibly cost saving). In selecting cost consequence analysis to report the results of these studies, the non-health benefits which have been reported are also captured.

Such a conclusion should, however, be treated with caution given the before and after design of the evaluations (rather than a controlled comparison). It is therefore difficult to assess to what extent the observed changes would have occurred in the absence of the intervention being investigated. An added difficulty of interpretation is that the reported results are not always specific about the time period over which changes are estimated to have occurred, the numbers who stand to benefit and the baseline from which changes have taken place. Moreover, any benefits attributed to the intervention may result from factors specific to a particular locality and may not be generalizable to other areas or settings. On the cost side, there are uncertainties such as incomplete knowledge about the resource requirements of the programmes.

It is therefore difficult to make general statements about the cost-effectiveness or otherwise of the programmes reported here (an issue which the Evaluation Reports did not seek to explore) and further research would be useful to quantify their costs as well as their health and wider societal benefits. Nevertheless, the Evaluation Reports and the evidence presented here provide an indication of the potential impacts of these programmes which local decision makers can use to inform investment decisions based on their own trade-offs between limited resources and benefits of various types.





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