

Prostate Cancer UK

**Community Support Services
Evaluation Report**

July 2015



**PROSTATE
CANCER UK**



Evaluation Services

Contents

Executive Summary	1
1 About this report	4
2 The CSS programme	5
3 Case study research and findings	15
4 Reflections from Prostate Cancer UK	23
Annex A: Case studies	28
Holistic therapies to improve the wellbeing of people affected by prostate cancer	29
Supporting men with advanced prostate cancer	37
Tackling emotional problems through counselling	43
Improving the cancer journey with Holistic Needs Assessments	55
Social prescribing to help men with prostate cancer	61
Encouraging healthy living	66
A whole-person approach to survivorship	72
Annex B: Outcomes measurement	77

Executive Summary

What are Community Support Services?

Community Support Services (CSS) is Prostate Cancer UK's programme to ensure the best diagnosis, treatment and support for all men with prostate cancer by working through regional hubs to commission and manage community support services to meet the needs of men closer to home and in their communities.

How do they work?

Prostate Cancer UK wanted to better understand local needs and provision of support for men with prostate cancer and their close supporters, recognising that care was inconsistent across the UK, especially in terms of non-clinical support and ongoing assistance with self-management, survivorship and living with cancer in the longer term. With that improved understanding, the expectation was that the programme could better meet local needs, by targeting, coordinating and influencing the delivery and development of services for men. The ultimate aim was to make high quality support accessible to more men and their families.

£3.83m of funding from the Movember Foundation between 2012 and 2015 allowed Prostate Cancer UK to establish six additional regional hubs to deliver the CSS programme. The activity has involved three strands of work:

- Local projects where a lead delivery partner (usually a voluntary sector or NHS partner) was commissioned by Prostate Cancer UK to provide services. In addition to funding, Prostate Cancer UK gave other support such as training and brokering links with other organisations. The commissioned activity is the main focus of this evaluation report
- Face to face activity undertaken by Prostate Cancer UK-employed nurses funded by Royal Mail (through one-to-one and group support) including nurse-led information stands and attendance at a number of support groups for men in Scotland, which are part of Prostate Cancer UK
- Collaborations and partnerships, mostly comprising activity with independent support groups across the UK that partner with Prostate Cancer UK, as well as wider partnerships with other organisations that support men with prostate cancer. Unlike the commissioned activity, these partnerships did not involve contracts or funding agreements. A separate evaluation has been conducted for this element of the charity's work.

How were they evaluated?

The evaluation has involved internal and independent external fieldwork and analysis:

- The analysis of CSS programme data centrally by Prostate Cancer UK, which provides an overview of programme performance (Section Two)
- An independent research exercise carried out by Cloud Chamber Limited, which involved fieldwork with 12 CSS services and the completion of 8 case studies highlighting examples of how the programme had worked in practice (Section Three, with all case studies annexed to this report)
- An internal workshop held in Prostate Cancer UK on 3 July 2015 to discuss learning from the programme, drawing on wider evaluation work conducted by the individual CSS regional managers (Section Four)

What are the outcomes?

The programme exceeded its targets for delivering support in one-to-one and group settings: 75,851 people benefited, against a target of 46,385.

A range of different outcomes were achieved by the programme's commissioned activity across key support themes:

- Self-management / health and wellbeing: helping men to go about their day-to-day lives, improving their mental and emotional wellbeing, and raising their awareness of the side effects of treatment and how to live more healthily
- Targeted communities of interest: specific assistance for black men and Gay and Bisexual men and Trans women to increase their access to support, and to ensure that health professionals and others have the knowledge to signpost people to the right services in a culturally appropriate manner
- Physical activity and fitness: improving men's physical wellbeing by raising their activity levels
- Psychosexual support: reducing men's stress, anxiety and depression and improving their relationships

What did we learn?

The findings of the independent case study work identified the following learning points (which may not be representative of the programme as a whole):

- The programme has delivered a wide range of services cost-effectively. This is achieved in part by piggy-backing or amending existing services, rather than creating entirely new ones; and by drawing on the support of healthcare professionals who give their time without charge to the charity
- Funding levels were about right for service delivery partners, although some underestimated development and ongoing management costs. Others underestimated the amount of time and effort required to promote a new service and encourage men to take part

- Funding timescales were too short to guarantee sustainable services and delivery partnerships. In many cases, services put a lot of resource into promoting services which are now no longer available, and this has strained some relationships. The experience has, however, provided Prostate Cancer UK with a wealth of different and effective service pilots from which the charity could draw in future
- Services have been more successful encouraging men to take part where they have been given little option by their clinicians. Face-to-face networking also works well, but it is resource-intensive and takes time to deliver results. Men's partners can be very important influences on men's decision to take part; they like to feel involved and also benefit from similar types of support
- A range of outcome measurement approaches was used, reflecting the variety of services (and potential benefits) on offer. While some services have good evidence on outcomes, other struggled for a variety of practical reasons.
- The personal stories of men who have accessed community services demonstrate how positive the experience can be on a very individual level. Where broader outcomes data is available, the wider benefits are clear too

What will we do next?

As a result of an internal reflection exercise, the following recommendations were made based on the programme's experience and its evaluation:

- Prostate Cancer UK now has a better understanding of the audience for community-based services, and can clearly define a target group of men who will be the focus of programmes in the future
- Support should focus on self-management and wellbeing, delivered through strong links with the NHS, and voluntary and community services locally
- Holistic care should be offered on an 'opt out' basis to remove ambiguity from the purpose of support
- A group approach to support should be encouraged as an introduction to holistic services
- The charity's community based programmes need to be better integrated with its national direction and profile
- Prostate cancer is a long term condition, and people should be supported through sustainable, relationships and services. The charity therefore needs to apply a long term strategy to partner development and service support
- Evaluation needs to be improved in order to help design programmes that have a coherent logic, as well as focusing resources on improving outcome measurement and making it more consistent

1 About this report

This report represents the final evaluation of Prostate Cancer UK's Community Support Services (CSS) programme, which ran for three years between 2012 and 2015. It builds on an interim evaluation report that was produced in April 2014.

The evaluation draws on three evidence-gathering exercises:

- The collation of CSS programme data centrally by Prostate Cancer UK, which provides an overview of programme performance. A summary of this information is provided in Section Two
- An independent research exercise carried out by Cloud Chamber Limited, which involved fieldwork with 12 CSS services and the completion of 8 case studies highlighting examples of how the programme had worked in practice. A summary of the findings is provided in Section Three, and the case studies are appended to this report
- An internal workshop held in Prostate Cancer UK on 3 July 2015 to discuss learning from the programme. The findings from this workshop are set out in Section Four

2 The CSS programme

2.1 Introduction

This section provides an overview of the CSS programme as a whole. The section has been completed by Prostate Cancer UK and not the independent evaluators.

2.2 Programme origins

The CSS programme was first established in April 2012 and ran to June 2015. Prostate Cancer UK wanted to ensure the best diagnosis, treatment and support for all men with prostate cancer. In order to better do this across the UK, the charity sought to expand from its London and Glasgow bases and establish regional hubs that could commission and manage community support services that would meet the needs of men closer to home and respond to local needs.

The expectation was that these hubs would enable Prostate Cancer UK to understand local problems, and then target, coordinate and influence the delivery and development of services for men, to tackle the issue of inconsistent care across the UK and promote evidence-based clinical pathways to improve the quality of care, and therefore making high quality support accessible to more men and their families.

Funding provided by the Movember Foundation from April 2012 onwards gave Prostate Cancer UK the catalyst for this nationwide expansion, providing funding to establish six additional regional hubs. A new Business Plan established the scope and ambitions for a new programme known as Community Support Services. It was established as a programme within the charity's Services directorate to be delivered by a team of Community Support Services Managers (CSS Managers) and Community Nurse Specialists on fixed term posts funded by Royal Mail.

2.3 Activity funded by the Community Support Services programme

The funding provided by the Movember Foundation (£3.83m) was used to support three main strands of activity supporting men in their local communities:

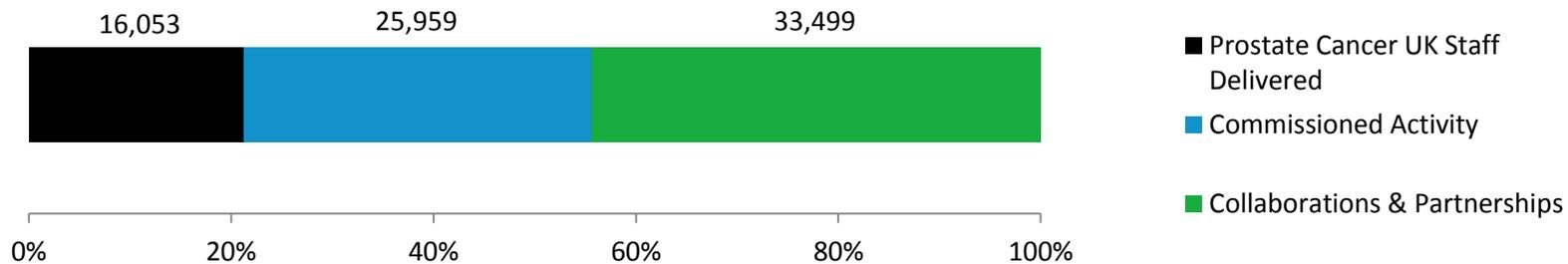
- **Commissioned Activity** – local projects where a lead delivery partner (usually a voluntary sector or NHS partner) held a contract with Prostate Cancer UK for the provision of services to men and their families. Prostate Cancer UK supported the local partner to deliver the service (e.g. by providing knowledge about the needs of prostate cancer, or brokering links between different organisations). Local partners were responsible

for managing the activity and carrying out reporting and generating evidence of impact, as agreed with Prostate Cancer UK, in proportion to the size and nature of the activity. Interventions were either longer-term projects commissioned according to a number of key themes (see below), or regional survivorship conferences (bringing together men and health professionals to share information about local support). The commissioned activity is the main focus of this evaluation report.

- **Staff Delivered Activity** – face to face activity undertaken by Prostate Cancer UK-employed nurses (offering one-to-one and group support) including nurse-led information stands and attendance at a number of support groups for men in Scotland, which are part of Prostate Cancer UK.
- **Collaborations and Partnerships** – mostly comprising activity at independent support groups across the UK that partner with Prostate Cancer UK, as well as wider partnerships with other organisations that support men with prostate cancer. Unlike the commissioned activity, these partnerships did not involve contracts or funding agreements. A separate evaluation has been conducted for this element of the charity’s work.

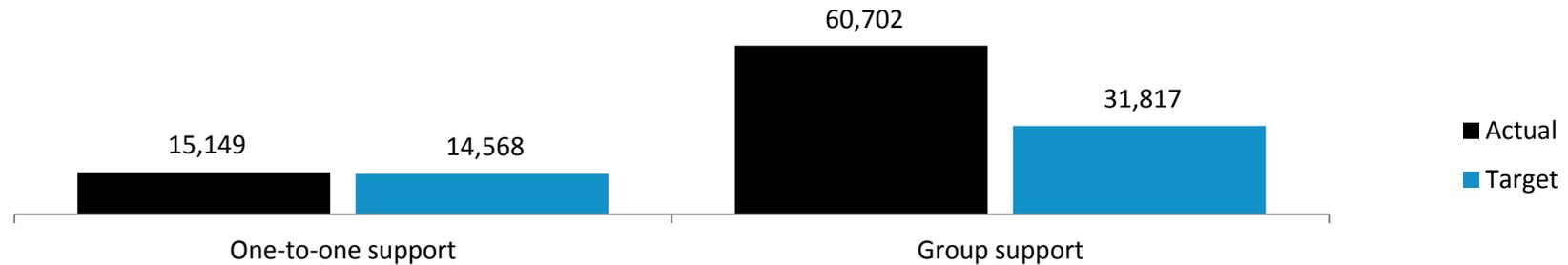
Figure 2-1 shows the overall number of beneficiaries in each strand of activity for the duration of the programme.

Figure 2-1: Number of beneficiaries by CSS activity stream, 2012-15



Prostate Cancer UK also set goals for the number of people who would benefit from support delivered one-to-one or in group settings. Figure 2-2 shows that we exceeded our expectations for providing support in group settings by 91%, and our expectations for providing one-to-one support were met.

Figure 2-2: Number of beneficiaries in one-to-one or group settings, 2012-15



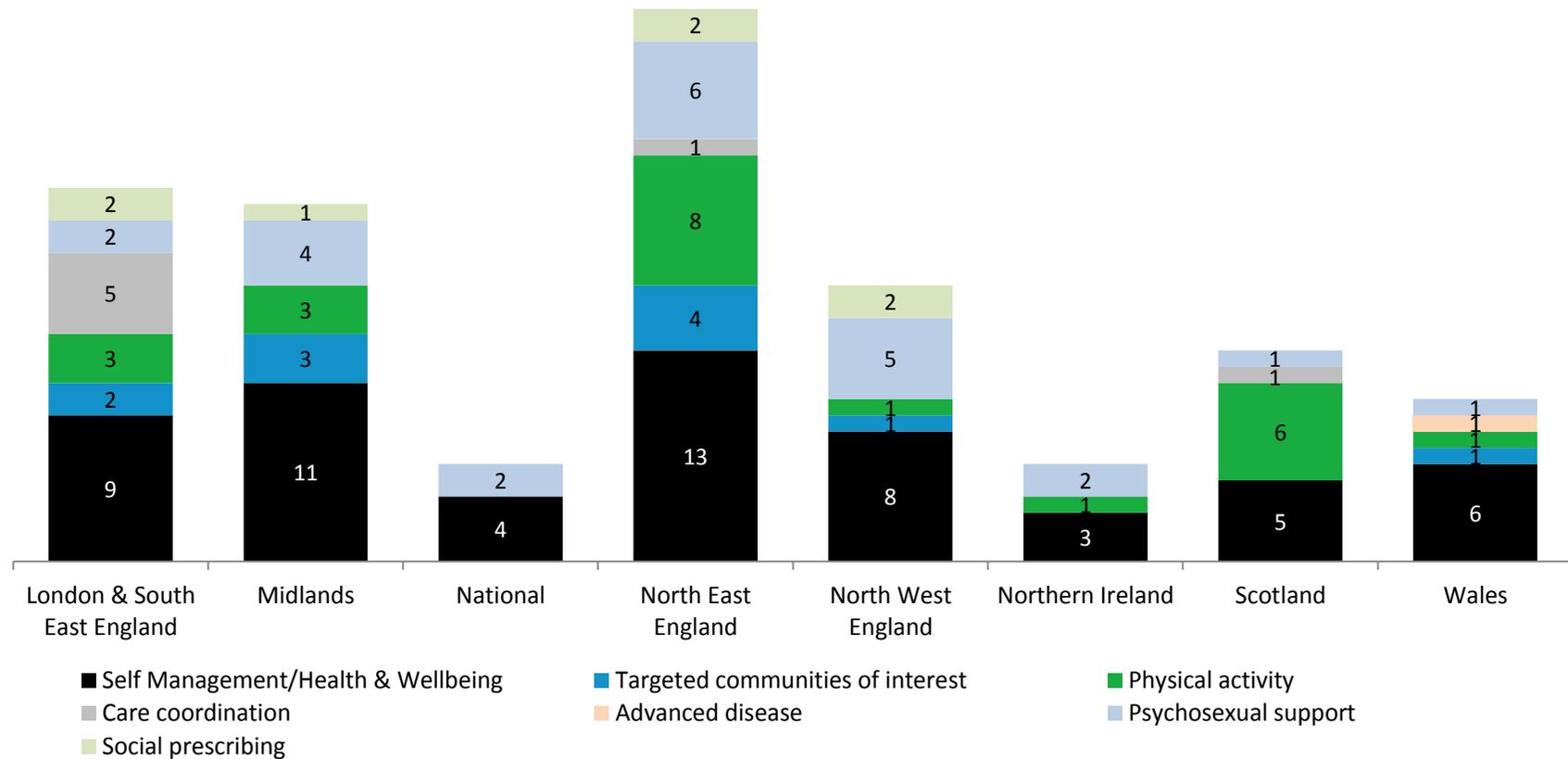
2.4 Analysis of commissioned activity

During the three years of the programme, a range of thematic projects or interventions were developed together with local partners. Prostate Cancer UK aimed to commission activity under seven main themes. Because the provision of more holistic models of care was a key principle for the whole programme, many projects aimed to address more than one theme. To aid our analysis, we worked with the CSS managers to categorise their projects according to their main theme. Because the projects or interventions were developed in partnership – attempting to identify problems and build from local needs - the themes also reflect the nature of demand for services that target different aspects of men’s long-term health. Most projects took a broad approach to self-management, health and wellbeing. The number of projects and themes are described below.

- **Self-management / Health and Wellbeing:** 59 projects aiming to deliver reliable and timely information and advice to men and family members on how to better manage their prostate cancer and existing or potential side effects of treatment
- **Social Prescribing (7) and Care Co-ordination (7):** projects that aimed to develop prostate cancer care pathways from clinics to community support thereby improving access to support available in local communities
- **Fitness and Physical Activity (23):** projects to support men to increase their physical activity levels and core strength, address the impact of cancer related fatigue and to promote emotional wellbeing
- **Psychosexual Support and Relationship Counselling (23):** improving men and their partners’ communication and address the issues men face
- **Communities of interest (11):** the targeting of Black men and Gay and Bisexual men and Trans women to address ingrained and long standing health inequalities

Figure 2-3 shows the number of projects according to their main theme and delivery region, and highlights the predominance of self-management, health and wellbeing interventions. Six projects were commissioned at a 'national' level with larger partner organisations such as Relate or Maggie's Cancer Care. There are fewer projects in Wales and Northern Ireland as these offices were set up later in the programme (in the case of Northern Ireland, only one full year of commissioned activity took place).

Figure 2-3: Projects by theme and geography, 2012-15



The largest share of people benefited from self-management, health and wellbeing projects, and almost half of the programme resources were directed to commissioning projects in this theme (Figure 2-4 and Figure 2-5).

Figure 2-4: Beneficiaries by theme

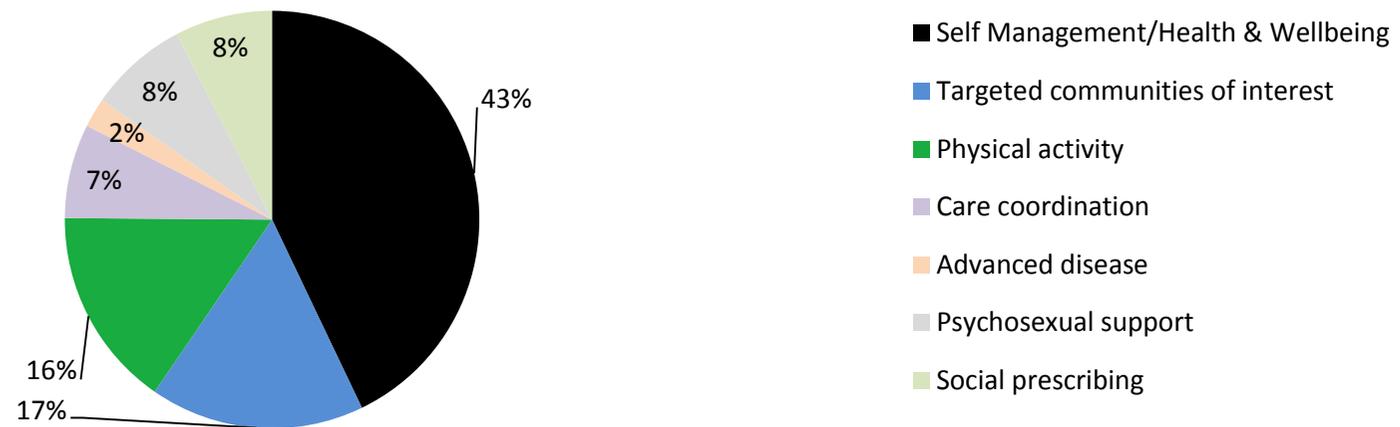


Figure 2-5: Beneficiaries and activity value by theme, 2012-15

Theme	Number of beneficiaries	Value (£000s)
Self-management/Health & Wellbeing	9,452	451
Targeted communities of interest	3,686	92
Physical activity	3,425	194
Care coordination	1,609	131
Advanced disease	501	11
Psychosexual support	1,698	233
Social prescribing	1,679	72
Total	22,050	1,185

2.5 Analysis of the outcomes of commissioned activity

Each project was asked to consider how it would demonstrate outcomes and impact and where possible, to use recommended validated tools to describe how many individuals had achieved each agreed outcome (following discussion with Movember at the mid-point of the programme).

Within each theme, because each project could address the needs of men and their families in varied ways, at different parts of the care pathway, there could be no 'one size fits' all' approach to measuring outcomes. However, as well as bespoke evaluation and follow up questionnaires, simple validated tools such as MYCAW and the Distress Thermometer we most often used to show change (examples are given below). Because of the varied nature of interventions and men and their families' length of involvement, change against a baseline could be measured at different times, according to the project. However, most of the outcomes we can see below reflect changes in men's health, knowledge or skills over time (rather than a measurement at a single time point).

As part of the evaluation, we categorised each of the outcome measures agreed with every commissioned project in each of the themes, to give an overall number for the number of men that experienced different kinds of benefit. Some men experienced more than one outcome, so the totals in the tables below refer to the total number of outcomes for men. More detail on the classification of themes, and outcome measurement tools, is provided in Annex B.

We have examined each of the four main themes of commissioned activity to show the outcomes for men and their families. For examples of activity under all the themes, described in much greater detail, please see the case studies in this report.

2.5.1 Self-management, health and wellbeing

The most commonly reported outcomes in this theme related to ability to go about day to day life, and improved mental and emotional wellbeing. (Figure 2-6).

Figure 2-6: Summary of outcomes for self-management / health and wellbeing

59 projects 9,452 beneficiaries £451,000 funding	
Key Outcome	Beneficiaries
Able to function/go about day to day life	3,611
Improved mental and emotional wellbeing	2,906
Awareness of and ability to access support services and information	1,261
Awareness and understanding of side effects of treatment and managing those side effects	1,204
Aware of benefits of healthy eating and exercise	786
Awareness and understanding of treatment options	777
Reduced stress and anxiety	362
Ability to share experiences/concerns	284
Awareness and understanding of risks and symptoms of prostate cancer	284
Improved physical wellbeing	249
Knowledge of local services (and how to access them)	185
Reduced isolation (from HPs/support services)	120
Awareness and ability to access support services and information	90
Improved local support	57
Improved relationships	17
New skills	7

Project example

Guy's and St. Thomas' NHS Trust developed a series of seminars available to men affected by prostate cancer who live in London. Each seminar aimed to improve the quality of life, increase understanding and reduce the anxiety of men choosing active surveillance and their partners. The course aimed to provide men with the tools needed during their prostate cancer survivorship journey. Each session was run by a specialist in exercise and cancer rehabilitation. Of 252 beneficiaries:

- 62% of men experienced improvement in the understanding of active surveillance
- 88% of partners / family members experienced improvement in the understanding of active surveillance
- 5% reduction in calls to Guy's Hospital helpline after the seminars - illustrating need was met

2.5.2 Targeted communities of interest

The most commonly reported outcomes in this theme related to increased access to services, increased awareness of risks, men benefiting from their health professional or support group leader having increased knowledge or confidence, as well as ability to function and improved mental and emotional wellbeing.

Figure 2-7: Summary of outcomes for targeted communities of interest

11 projects 3,686 beneficiaries £92,000 funding	
Key Outcome	Beneficiaries
Men have increased access to services	1,935
Men are aware of risks	1,855
Health professionals/support group leaders/volunteers have knowledge and confidence to provide/sign post to accessible and culturally appropriate services	1,263
Able to function/go about day to day life	1,198
Improved mental and emotional wellbeing	1,198
Reduced social isolation	1,198
Men are aware of diagnostic options	657
Knowledge of benefits of being active/physical activity	225
Men are aware of support services/information they can access	225
Services developed take account of the views and needs of men and their families	164
Improved emotional and physical wellbeing	85
Opportunities for peer support/social interaction	85

Project Example

Easington Lane Community Access Point aimed to provide men with the tools needed to support their physical and emotional health. By connecting with people, developing relationships and being active, participants could improve their health and wellbeing. This service included numerous activities such as practical tools to support recovery, one-to-one and group support from clinical nurse specialists, healthy eating and regular exercise programmes, and self-help techniques to help manage stress and anxiety. Of 1198 beneficiaries:

- 45% experienced a reduction in the concerns that they identified via the MYCAW tool
- 5% experienced an improvement in wellbeing, as measured by MYCAW

2.5.3 Physical activity and fitness

Perhaps unsurprisingly, the most commonly reported outcome under this theme was improved physical wellbeing, as well as improved access to statutory services. 44 people had a measureable improvement in their physical activity level, and 99 people had improved emotional wellbeing – highlighting the value of physical activity programmes in improving emotional health.

Figure 2-8: Summary of outcomes for physical activity and fitness

23 projects 3,425 beneficiaries £194,000 funding	
Key Outcome	Beneficiaries*
Improved physical wellbeing	186
Increase access to statutory services	116
Improved emotional wellbeing	99
Increased activity levels	44
Awareness and understanding of treatment options	35
Health professionals/support group leaders/volunteers have knowledge and confidence to provide/sign post to accessible and culturally appropriate services.	35
Knowledge of benefits of being active/physical activity	35
Aware of benefits of healthy eating and exercise	26
Services developed take account of the views and needs of men and their families	21
Fatigue management	18
Improved mental and emotional wellbeing	6

*For many of these projects their individual project outcomes were coded into only a one or two of the Key Outcomes and due to the data tidying (explained in the Note) beneficiaries were counted once per Key Outcome within the Project.

Project Example

KA Leisure offered free physical activity programmes available for men undergoing prostate cancer treatment in North Ayrshire. Physical activity has been shown to help alleviate the symptoms of fatigue and can help aid recovery. The scheme aimed to help men find a suitable activity to complement their treatment and provide an opportunity to develop new skills. Once referred, patients received up to three one-to-one consultations with a member of the KA Leisure team. Patients were then signposted to an activity and offered a pass that will allow them to attend up to 12 gym sessions. Patients had the opportunity to continue their physical activity programme by being referred onto the Active North Ayrshire exercise scheme. There were 20 beneficiaries and all of them experienced:

- Improved emotional wellbeing
- Improved physical activity levels
- Increased access to statutory services

2.5.4 Psychosexual support

The most important outcomes reported include acceptance of one's condition, reduced stress and anxiety, and improved relationships. It is not clear why there is a lower number of reported outcomes for this theme when compared to the others.

Figure 2-9: Summary of outcomes for psychosexual support

23 projects	
1,698 beneficiaries	
£233,000 funding	
Key Outcome	Beneficiaries
Acceptance of condition	129
Reduced stress and anxiety and depression	122
Improved relationships	97
Ability to share experiences/concerns	12
Improved emotional and physical wellbeing	7

Project Example

The Men's Action Network in Londonderry, Northern Ireland, helped men affected by prostate cancer through face to face counselling sessions, telephone counselling sessions, and referrals to other sources of cancer information and services. Counselling can explore the many aspects of prostate cancer diagnosis and how it affects relationships. We found that:

Beneficiaries had an improved acceptance of their condition:

- 100% reduction in anxiety
- 100% reduction in depression
- 74% management of expectations
- 100% of beneficiaries had reduced stress, anxiety and depression
- 73% had improved relationships

3 Case study research and findings

3.1 Research requirement

Cloud Chamber Limited was commissioned to carry out independent research as part of this evaluation, focusing on the delivery of 8 case studies of 12 CSS-funded services run across England, Scotland and Wales (where similar services were delivered in different locations, these have been summarised in a single case study). The case studies were expected to draw out:

- How the services had performed, including management and monitoring processes and the relationship with Prostate Cancer UK
- How men with prostate cancer (and their supporters) had benefited from the services
- What lessons could be learned from the experience: by Prostate Cancer as well as the service delivery organisations
- What, if any, assessment could be made about value for money

Across the 12 services, we completed the following:

- A review of all relevant documentation and data for each service, focusing on the final year of delivery (2014/15)
- Interviews with around 30 deliverers, service users and healthcare professionals
- Eight comprehensive case studies, including individual stories of men with prostate cancer
- Delivery of a findings workshop with Prostate Cancer UK in July 2015

3.2 The case study sample

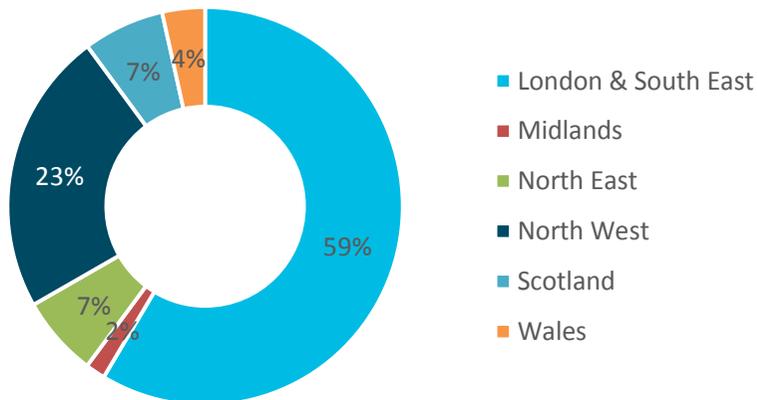
Selection of the case studies was made by the CSS team at Prostate Cancer UK in consultation with the evaluators. The sample was designed to provide a wide range of service types and deliverers in different geographical locations. No services in Northern Ireland were selected because activity in this region started later than elsewhere. A summary of the selected services is provided overleaf.

Service	Main delivery partner
Active Surveillance Seminars	Guy's Hospital
Health and Wellbeing Clinics, Living Well Courses	Penny Brohn Cancer Care (two locations)
Improving the Cancer Journey	Glasgow City Council
Relationship and Psychosexual counselling	Relate (four locations)
Pro-Active	Cheshire and Wirral NHS
Counselling and Stress Service	George Thomas Hospice Care
Counselling and Cancer Services	Age UK Northumberland
Healthy Living Programme	Age UK Wakefield

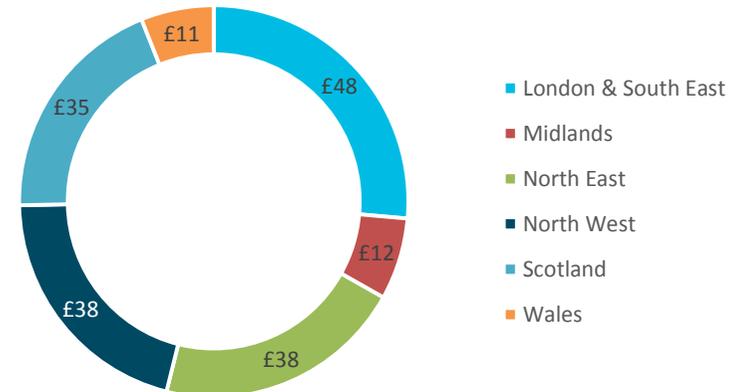
2,226 service users

- **66% were men with prostate cancer**
- **One in five were Afro-Caribbean men**
- **96% of friends and families were women**

Service users by location



Funding by location (£000s)



3.3 Case study findings

Each service was researched in some detail, and the remainder of this section summarises some common key findings from across the 12 services. The views are those of the independent evaluators and it should be noted that these findings do not necessarily reflect the performance of the programme as a whole.

3.3.1 Funding – Prostate Cancer UK’s perspective

At the level of individual services, CSS has been cost-efficient (i.e. the amount of funding has been proportionate to the volume of activity delivered). Only where services have really struggled to deliver on output numbers have they begun to look expensive compared to benchmark indicators. The charity has achieved this cost-efficient delivery because of

- Building the new services on top of existing services, thereby reducing start-up costs and other overheads
- Not having to pay for the costs of healthcare professionals (or the costs of providing cover for their work while they are engaged in the CSS programme)
- Where they exist, linking services to healthcare professionals funded by the charity who have tended to be enthusiastic promoters of the CSS programme

We should note that our calculations do not include the costs of running the CSS Manager network, or any other relevant Prostate Cancer UK central costs (e.g. marketing and communications), which would increase the unit costs of delivery if included. Prostate Cancer UK might wish to consider collecting these costs in future to enable evaluations to determine a more accurate measure of cost-efficiency.

3.3.2 Funding – service deliverers’ perspective

Overall, CSS programme partners were content with the size of Prostate Cancer UK’s financial contribution, relative to the type and volume of activity the charity was expecting to be delivered in return; and the extent of monitoring and administration that was required.

There were two areas where some deliverers under-estimated costs:

- Management costs: some partners underestimated the amount of management time and effort required to set up, and then oversee their services. The size of each contract was not sufficiently large to allow partners to fund additional management posts, so oversight was an

additional responsibility on existing staff. Smaller organisations found this harder and, in our wider experience, often struggle to estimate and apportion central/overhead costs

- Marketing and promotion costs: especially where services were entirely new, some partners failed to appreciate the amount of effort required to bring their service to the attention of men with prostate cancer. This was particularly difficult for those partners who were not already familiar with working in the prostate cancer field. Budgets tended to focus on the costs of printed materials (leaflets and posters) rather than the staff costs of visits to support group meetings and cancer clinics

3.3.3 Funding timescales

The overwhelming view of those we spoke to was that the funding timescales were too short for the CSS programme for a number of reasons:

- Partner relations: there has not been enough time to establish a strong relationship between Prostate Cancer UK and service delivery partners. The relationship has often seemed more transactional than strategic or long term because of the timescales: based on the case study evidence, the programme looks less like a strategic investment in prostate cancer services and more like an output (or outcome) purchasing process
- Service promotion: it took many of the delivery partners much longer than expected to promote the service and gain traction among men with prostate cancer. These longer lead-in times further reduced the window for service delivery. It has also meant that a lot of promotional materials remain within the prostate cancer care space (e.g. leaflets with support groups) but there is no longer a service attached
- Further cost-efficiencies: new services tend to have high start-up costs, which can make short term initiatives look comparatively expensive (even though cost efficiency does not seem to have been a problem for the services we studied). Longer timelines allow a service to spread these costs, and generally to become more efficient through experience and review
- Service sustainability/legacy: there are few examples of services that will continue without ongoing funding from Prostate Cancer UK (e.g. Active Surveillance at Guy's Hospital). Building a sustainable service takes time: establishing a presence, and creating an evidence base of success to take to other funders
- Organisational reputation: the decision to end funding for many services in early 2015 was, according to delivery partners, not handled well and they had originally been led to believe that funding would continue. It may also be that the terminology has had a role in giving partners misplaced expectations of continuity funding: 'service' suggests a constancy of delivery, whereas 'project' or 'initiative' would have signalled a shorter term approach

We recognise that some of these criticisms are based on an assumption of the CSS programme being a strategic investment, rather than a test-bed for new initiatives, and that the latter may be a better description of Prostate Cancer UK's original intention. Whatever the intention, the short term nature of the funding timescales has nevertheless limited the learning from the exercise and has not bolstered the reputation of the charity as a funder of services.

3.3.4 Reaching men

The services have had varying success in reaching men with prostate cancer but on the whole, they have been more successful:

- Closer to the clinical pathway: services operating in more of a clinical environment (like Active Surveillance, which takes place in Guy's Hospital) seem to find it easier to engage men. This may be because men are more likely to regard such services as an obligatory part of their treatment, rather than an optional extra. Service partners have noted how the cohort of men with prostate cancer is not a group that naturally goes out looking for support, but that they do respond well to direction from medical professionals
- With plenty of face-to-face networking and promotion: several of the services have noted that the most successful ways of promoting their service have involved going out and meeting support groups, clinicians, and others working in prostate cancer treatment and recovery. In part, this has been a response to partners recognising the complexity of the prostate cancer treatment and care pathway, where there is no single point where a service can guarantee reaching all men with prostate cancer

There is evidence from the evaluation that tells us something about the types of men who are accessing these services (although it should be noted that the range of services was wide, so generalisations should be read with caution). In particular, they tend to be younger on average than the cohort of men with prostate cancer. More than half (51%) of the case study service users with prostate cancer were under 60, compared to 31% who are under 64 years old nationally (national figure from Prostate Cancer UK). This may be due to a couple of factors:

- Their point on the treatment pathway: several of the services were likely to be more suitable to men who were still in treatment, or who were coping with the immediate side-effects (e.g. incontinence), which may have favoured a younger cohort
- The focus on 'holistic' treatments: the holistic approach, involving a range of treatments from massage and reflexology, through to personal and emotional counselling, might be less accessible to an older generation of men not used to considering their own physical health in the wider context of their personal wellbeing

3.3.5 Partner selection

The CSS programme has worked with a wide variety of service delivery partners. We have identified three broad groupings, each of which has brought its own strengths:

- Cancer-focused, like Penny Brohn, where there is plenty of experience of supporting people with cancer and it has been a relatively straightforward process to 'bend' existing services in the direction of men with prostate cancer.
- Service-focused, like Relate, which has an established and well-developed service and where the main challenge has been to bring this service to the attention of men with prostate cancer who might not consider it something that would suit them or that they could benefit from
- Community-focused, like Age UK, where the wider local networks are good, but where individuals with prostate cancer can be difficult to identify within an existing client base of older people

3.3.6 Measuring outcomes

The picture on measurement of outcomes is mixed. As the previous section demonstrated, a very wide range of outcome measurement tools were trialled across the programme so an overall, consistent view of performance is hard to identify. This is also true of the case studies. Some have successfully collected and reported evidence, and these have tended to be service run by larger organisations with prior experience of service delivery (and/or funder requirements to demonstrate outcome evidence).

- Target-setting: some services were given fixed numerical outcome targets, while others were set as proportions (e.g. 50% of beneficiaries to improve their mental wellbeing). Fixed number targets can look unduly negative where a service has not achieved its participation volumes. Equally, proportions hold less value when based on very small numbers
- Recording: the monitoring data provided to Prostate Cancer UK by individual services gives outcome numbers, but no detail on which measurement tools have been used, or when/how they were used (e.g. the duration between a pre- and post-participation questionnaire)
- Practicalities of data collection: some delivery partners have struggled to secure the participation of beneficiaries in outcome measurement, either because service users have refused/avoided the process, or because deliverers have not wanted to push the matter. It is clear that some service users are uncomfortable with what they regard as a clinical-style of questioning for a service that is otherwise trying to be non-clinical in tone. Furthermore, several of the services offered a free course of treatments or sessions, not knowing in advance how many an individual would take up. This meant that there was no set 'final' session during which outcomes could be reviewed; and the services have generally not kept in touch with their service users once they stop coming, removing the potential for subsequent follow-up

Beyond the CSS programme, there is a much wider challenge in health and social care around measuring the outcomes from holistic interventions. First, the portfolio of holistic treatments is a very wide one, and each has a potentially different set of outcomes. Secondly, the kinds of benefits that people ascribe to these interventions can be very difficult to measure and aggregate (although they make very compelling personal stories). For example, people find it hard to describe the value of being able to tell their friends and families about their cancer, or the importance of still being able to work. This is a point that several service delivery partners made to us.

We would speculate that the relatively small amount of funding provided to each service was insufficient to incentivise a more thorough and consistent approach to outcome measurement (as opposed to output measurement, where there was more success). Encouraging service deliverers to consider their longer term sustainability might encourage them to place more of a focus on outcome measurement as a means of demonstrating effectiveness and securing future funding from other sources.

3.3.7 Making a difference to men and their supporters

The personal stories of men who have accessed community services demonstrate how positive the experience can be on a very individual level. Where broader outcomes data is available, the wider benefits are clear too. Overall, we would make the following observations about what these case studies tell us about how services like this can maximise their impact in future:

- Men like choice: holistic approaches have gone down well with service users. Men like to feel empowered to make decisions about how they engage, and with what, rather than it being stipulated; the service feels tailored to their needs as a result. This is also true with counselling, where men want to feel that they are setting the agenda (even if they find it hard to articulate their needs at the outset)
- Men like being in groups: men really value the opportunity to speak to their peers and share stories and concerns about how prostate cancer affects their lives. This also helps when it comes to asking difficult questions. As one nurse put it, there is usually one person in a group who will ask the question that others were too embarrassed to ask; but they all benefit from the answer
- Men like to balance focusing on, and forgetting about, their cancer: again, holistic approaches work well by providing detailed information on treatment and care, which men will often focus on; but also offer opportunities to completely forget about, and not be defined by, their cancer through relaxation, exercise, or social interaction
- Partners and families like being involved: the services have supported many friends and partners of men with prostate cancer. The case study research has not involved much direct contact with them, but they do appreciate being part of the holistic approach and are often instrumental in persuading men to take up services in the first place

3.3.8 Saving money

The evidence of community services saving money in the wider context of health or public spending is limited. This is not a criticism as the programme was not designed with this as a driving objective. However, it is an increasingly ubiquitous element of health and social care delivery, even for charities, and should be considered as a more integral part of evaluation of similar services in future.

In the absence of hard data, we can only highlight a few areas where service delivery partners expected their services to have the potential to deliver savings:

- Improving service efficiency, for example by seeing men in group sessions, clinicians may be able to reduce the number of individual appointments that each service user would otherwise require
- Reducing patient demands on the system by improving their capacity to self-manage, for example increasing their physical activity, improving their diet and relieving stress and anxiety that might otherwise require medical intervention
- Helping men make the right choices and avoid unnecessary procedures, for example encouraging men to remain on active surveillance rather than opting for surgery

It should also be remembered that holistic approaches can result in additional costs, as well as savings. For example, offering a signposting service like that provided by Age UK can increase the burden on other services because they can highlight areas of need that would have otherwise gone undetected and unmet. Furthermore, improving people's access to welfare benefits increases the cost to the public sector, even if it is providing people with the financial support to which they are entitled.

4 Reflections from Prostate Cancer UK

This section sets out some concluding thoughts and recommendations, as authored by Prostate Cancer UK, not the evaluators. It is based on the findings of a workshop held with Prostate Cancer UK's CSS managers on 3 July 2015 to discuss learning from the three years of the programme. This drew on wider evaluation and reflective work undertaken by the individual CSS managers, as well as the findings of the case study research.

4.1 We should clearly define a target group of men who will be the focus of future programmes in the community

As a result of the CSS programme, we now have a much better understanding of the potential audience for community-based services. Demand from men, the NHS and the local voluntary sector is clear: future programmes should target diagnosed men who are in need of holistic support to help them make decisions about their treatment; and who need to recover and manage their side effects in the immediate months after treatment.

4.2 We should serve this target audience by creating strong links with the NHS, and voluntary and community services locally

Our community services were by necessity experimental and we commissioned a wide range of activity. This has helped us to learn 'what works' but did not make for a particularly logically-designed or complementary set of activities in a programme. The NHS is focused on providing treatment and support groups can be useful source of support for men whose prostate cancer is a long-term, stable condition. We have the potential to link the two, working between local NHS and voluntary sector partners to encourage the former to adopt more holistic practices and generate referrals into tailored, supportive services; and work with the latter to increase their capacity and skills to deal with prostate cancer. This has been shown to result in pathways of care that give clinicians and men alike the confidence to draw on support outside of hospital, better meeting the 'whole person' needs of men with prostate cancer; and by demonstrating success, provide a way of building local services and relationships that can be sustained. But there is no easy route to fill these gaps in care if the holistic services or understanding of holistic needs do not exist locally - a developmental approach is the only possible way. Future programmes based on these principles will be aligned to a national agenda around improving survivorship and moving more care into 'the community', whilst being responsive to local need.

4.3 We should focus on self-management and wellbeing

Community services have shown that men want information to self-manage, as well as time, support and expert assistance to arrive at decisions that they are comfortable with. Feedback from service users showed that they do not have enough of this at the moment, and we know the NHS struggles to develop holistic pre- and post-treatment advice services because of the overwhelming demand for acute care. Men also say that they

want a better and more consistent experience in primary care. This learning also fits with what the charity has learned from delivering its other services too (education for health professionals, and its own specialist nursing service).

4.4 We should work with local partners to offer holistic care on an ‘opt out’ basis so as to remove ambiguity from the purpose of support

We should not offer (or encourage others to offer) ‘help’ but rather focus on support that is pitched as practical or factual in content: men are not necessarily able to identify what lies at the root of their own concerns about their cancer, and we have shown that framing an introduction to holistic self-management support in this way, as part of a clinical pathway, increases uptake.

4.5 We should encourage providing support and advice to men in groups as an introduction to holistic services

Community services have shown that group-based approaches to providing information and support, and introducing men and their partners to holistic services in this way, are effective. Clinicians (especially a CNS) and partners are important for bringing men ‘through the door’ and their involvement, at the outset, is important in encouraging men to take up community based services as part of a holistic needs assessment and care plan. Facilitated groups have been shown to be effective because they offer men in a similar position in their cancer journey to talk to each other and look at treatment and care options from a range of perspectives - and can build on existing relationships that men might develop with each other in the course of their treatment (e.g. in radiotherapy). Such ‘group support’ is distinct from the longer-term wellbeing that established support groups can foster, but in which decisions about immediate treatment or managing side effects are often not the main focus of participants’ energies. In some cases, workshop participants thought that facilitated groups could be supported to evolve into support groups; this happened in some instances as a by-product of our community services.

4.6 We need to improve the integration of community based programmes with our national direction and profile

The delivery of the CSS programme has been marked by missed opportunities to align local and national activity. This is about more than the charity becoming less ‘London centric’ which has been noted across much of our evaluation work, or making sure that regional relationships are managed in a coherent and unified way; it is about making sure that its future national strategy is well placed to take advantage of opportunities, policies and events that are already in place locally. The national organisation has a strong call to action and a brand that lends itself well to supporting local initiatives: but it needs to learn to ‘piggy back’ better on local service / NHS activity that is already taking place around the year, and allow for more flexibility in the development of long term initiatives so they take account of local and regional intelligence.

4.7 We should build better relationships with local clinicians by providing expertise and support where their skills are strongest

The CSS programme generated a great deal of learning about making a coherent and attractive 'PCUK offer' to local clinicians. As well as allowing time to build trust (a key point in the interim evaluation report), a focus on the patient perspective was thought to be important in exerting influence, and developing work packages with local stakeholders so they take account of local needs (e.g. tariffs in England). Lightening the load by saying 'can you refer' is more productive than saying 'this is what has to change'. It was also thought that a pitch around developing non clinical pathways of care would give purpose and focus to Prostate Cancer UK's role, and allow for us to shape a new programme around specific ideas or 'products' for improving holistic care without being prescriptive as to the exact means of delivery in each local area.

4.8 We should highlight how prostate cancer is a long term condition that affects more prominent agendas for local partners and commissioners, in order to build sustainable relationships and services.

Prostate cancer is usually not the highest priority for local NHS commissioners or the voluntary and community sector. If our initiatives and programmes are to lead to attracting funds from other organisations and more sustainable services, the 'pitch' to local partners has to meet their agendas half way. For example improving prostate cancer care can be a part of themes like healthy ageing, older people's health, better self-management, anxiety and depression, and so on. Using these themes as a 'hook' for interventions, as well as making sure that local evaluations meet local NHS criteria, will help to increase sustainability.

4.9 Our future work must build on the specific successes of the current programme

An important success of the current CSS programme is the links and services that were developed for specific communities. If working with 'targeted communities of interest' is to be part of our new strategy, the opportunity to deepen the relationships built via the CSS programme should be taken up. For example, GBT sector partners are keen to work with us on training health professionals, delivering survivorship support, shaping information resources for trans women, etc. To date the Prostate Cancer UK has focused on 'raising awareness' of prostate cancer among these groups: now the CSS programme has provided an opportunity to build tailored survivorship and wellbeing initiatives for these groups that goes beyond simply raising awareness, to making us part of the solution.

4.10 We need to use our community services to fight ageism in the provision of services, which affects the quality of prostate cancer survivorship care

A lot of the feedback from service users and partners revealed many ingrained, and institutionally ageist, thinking about older men's needs - particularly in respect to sexual activity and recovery after treatment; an approach to patients that can be paraphrased as 'you should be happy you're alive'. Older men's sexual function and health needs are often overlooked or ignored, rather than treated as a major contributor to poor quality of life. Tackling this has been a key underlying theme of our support, and this has revealed a demand for a greater focus on this in future programmes.

4.11 We should apply a long term strategy to partner development and use objective criteria to select those local partners with whom we choose to build relationships

Many of the challenges in local delivery arose from a lack of expertise among local partners in working with the NHS or men with prostate cancer (which we had to work to remedy) or a lack of proactivity among partners who saw little incentive in a short term funding model to improve or change the way they worked. A firmer, multi-criterion approach to partner selection should be a priority in future, leading to a tailored and jointly owned plan to develop the capacity of each of Prostate Cancer UK's partner organisations. Whilst the promise of long term funding (subject to ongoing success) could underpin this, it is equally important that contract negotiations are focused on an honest appraisal of partners' skills, which can be the basis of development activities (e.g. training on prostate cancer, provision of networking opportunities) which can be slowly tapered off as activity develops. The short-term nature of CSS funding meant that such approaches could not be tried in the current programme. The most successful partners were thought to be flexible and responsive, with a strong leadership and sense of mission / aims (the same of course applies to how we ought to behave).

4.12 We must improve our evaluation, beginning with designing programmes that have a coherent logic, as well as focusing resources on improving outcome measurement and making it more consistent

A major deficit of the current programme has been the inability of its evaluation to meet the multiple and varied needs of a) funders (who want evidence of long term impact), b) internal Prostate Cancer UK teams (e.g. communications, policy and influencing - who want good practice case studies and 'good news stories'), and c) local NHS organisations and commissioners (who want robust business cases, replicable business models, etc.). Greater clarity as to the purpose and aims of the programme, and from there, greater clarity as to the purpose and mechanism of evaluation, is essential to any future programme - so that resources for evaluation can be focused appropriately. A more consistent programme and fewer,

longer-term, developmental relationships with local community partners would also enable us to have more influence over local evaluation, enable better quality evaluation support to be planned for and resourced, and more consistent evaluation tools to be used to measure impact and outcomes across the programme.

In addition to these high level findings, it should be noted that, through the CSS programme, Prostate Cancer UK has developed a number of effective service pilots and models of delivery, across a wide range of areas which the charity can use to inform and support prostate cancer patients and treatment pathways in the future. Through the various streams of evaluation work, we have identified a number of models for delivery across our commissioning themes, which proved successful in supporting men and others affected by prostate cancer in a variety of ways. These models (with supporting evidence) provide powerful examples of what can work for men and should form the basis of future work to influence and deliver change.

Annex A: Case studies

Holistic therapies to improve the wellbeing of people affected by prostate cancer

The Pro-Active service provided holistic therapies (massage, reflexology, physical exercise, etc.) to men with prostate cancer and their partners in Cheshire and the Wirral. The service helped to relieve the stress and anxiety associated with living with prostate cancer.

The service

The Pro-Active service was delivered by the NHS through two Healthy Living Centres (HLCs) in Chester and Ellesmere Port between 2013 and 2015. The HLCs were already a local source of information on health and wellbeing, hosting a range of other organisations and services working in the field. Funding from Prostate Cancer UK allowed the HLCs to extend their existing, and very popular, holistic therapies service free of charge to men with prostate cancer and their partners. The HLC in Ellesmere Port already hosted local prostate cancer support group meetings, so the location made a lot of sense.

Pro-Active provided free introductory group sessions about holistic therapies like relaxation, head massage and reflexology. Men with prostate cancer and their partners then had free access to one-to-one sessions with a holistic therapist, a local gym, as well as other events and activities.

The benefits

Men and their partners said that Pro-Active gave them welcome relief from the stress and anxiety caused by living with prostate cancer: the diagnosis, its treatment, and the side-effects. They liked the fact that the service wasn't medical and focused on them rather than the cancer.

Some men said that they were sleeping better as a result of the relaxation exercises; one man had been able to return to work because he was sleeping properly.

Some men said that speaking to the holistic therapist about their cancer made it easier to discuss it with family and friends.

Men who used the gym got fitter and stronger. Some said that they had been able to reduce their medication (like statins) as a result. Others said that healthier eating and more exercise helped them to control their diabetes better.

What worked well

Pro-Active was easy to set up. It took an established and well-respected local service and directed it at people affected by prostate cancer. Prostate Cancer UK knew that the HLCs would deliver it well without the need for a lot of extra effort by the charity.

Running Pro-Active in a location already used by a prostate cancer support group helped to publicise the service among local people affected by the disease. The group put details of the service in an information pack for men who were newly diagnosed with prostate cancer.

Providing a menu of options gave men and their partners flexibility to choose the therapies that suited them best. It also allowed Prostate Cancer UK and Pro-Active to test the demand for different services and treatments. Some were very popular – there were more than three times as many one-to-one holistic therapy sessions than had been planned – some less so; ear acupuncture, which some men find helps them to manage their pain, had no take-up at all.

Pro-Active delivered more support than it planned to, making better use of the funding it received from Prostate Cancer UK.

What could have been better

Short term funding is inefficient because it takes time for people to become aware of services like Pro-Active, and to build up the confidence to approach someone for help. This is particularly true of men.

Outputs

Pro-Active delivered more sessions than expected in all areas except for ear acupuncture, where there was no take-up. One man said of acupuncture “I’m a coward, it didn’t appeal to me”, but more generally it is unclear why this new element of the service attracted such low interest.

The most popular and successful area of the Pro-Active service was the range of therapies provided by the HLC’s experienced in-house Holistic Therapist working two days a week for the project. These saw the highest number of sessions delivered, and the most positive feedback from users.

Output performance

Outputs	Target	Actual	Variance
Physical activity sessions	50	169	+119
Holistic therapy sessions	80	260	+180
Relaxation sessions	10	14	+4
Acupuncture sessions	55	0	-55
Total number of one-to-one sessions	135	255	+120
Number of group sessions	5	8	+3

Source: Prostate Cancer UK quarterly provider monitoring reports

Pro-Active was deliberately run as a flexible and responsive service, offering a menu of different services and support mechanisms to people affected by prostate cancer which could be adapted based on the level of interest and demand. As one member of the delivery team put it: “People don’t always like the things you think they will, and you may need to offer more of what they do like...You need to listen to people”. In practice, for example, it became clear that men weren’t engaging in healthy eating sessions, or acupuncture, so effort was switched to more activity around holistic therapies.

Management and monitoring

The service delivery team found Prostate Cancer UK’s monitoring requirements straightforward. They used the Warwick-Edinburgh Mental Well-being Scale as a means of quantifying the benefits of the service to its users. Pro-Active over-achieved with regard to its targets on mental and physical wellbeing (see table overleaf).

Outcome performance

Outcomes	Target	Actual	Variance
Participants will have a greater sense of physical wellbeing, including increased levels of regular exercise	20	27	+7
Participants will have a greater sense of mental wellbeing, including reduced anxiety	45	69	+24

Source: Prostate Cancer UK quarterly provider monitoring reports

Value for money

Budget suitability

The Pro-Active team thought that the budget was a realistic one given the targets and expectations placed on them by Prostate Cancer UK. The sub-contracted nature of parts of the service meant that costs were proportionate to the amount and type of support delivered (i.e. sessions were only paid for when delivered). The service manager at the HLC considered that her own time supporting the service had not been fully accounted for in the funding, but to a great extent this could be considered part of her wider health promotion remit.

Cost-efficiency

The service was delivered more cost efficiently than planned, having provided more sessions than originally anticipated. The table overleaf provides estimates of the different costs per session or per person for different elements of the service. The original budgeted cost per session for holistic therapy and relaxation was £25 and £9 for the physical activity sessions (excluding overheads like publicity and advertising). Even with overheads factored in proportionately to the number of sessions, the cost per session/service user was lower than expected. Advertising and publicity took more than one third (36%) of the budget, representing a significant proportion of the whole budget. However, it does seem to have generated high participation rates. If the service had continued to be supported by Prostate Cancer UK, we would have expected to see a reduction in the amount of publicity required as Pro-Active became an established and well-known local service.

Cost per session/service user (actuals)

Service element	Number	Cost	Cost per session/service user	
			Session only	Including overheads
Holistic therapy and relaxation sessions*	274	£3,981	£14.53	£18.30
Physical activity sessions	169	£478	£2.83	£6.60
Total individual service users/full delivery costs	61	£7,000	-	£114.75

Source: Prostate Cancer UK quarterly provider monitoring reports

*Combines group relaxation sessions and one to one therapies

These figures compare favourably with similar commercial (and publicly-subsidised) services. While costs vary dramatically from service to service, and location to location, the cost of a 30 minute Indian head massage session ranges from about £10 to £30/£40, so Pro-Active has been delivering at the mid-to-lower end of the scale. Gym membership costs (pay per visit) vary even more widely depending on the extent (or absence) of public subsidy and the facilities on offer, so comparison is very difficult. However, we have found few that offer a pay per visit service of less than about £8 (the cost to the user).

Cost savings

The service delivery team considers that Pro-Active has the potential to save the health and social care system money by improving the wellbeing of prostate cancer patients and their supporters, and thereby reducing their likelihood of developing depression, anxiety and similar mental health issues. However, there is no evidence to confirm that this has actually been the case.

Future funding and delivery

With the funding from Prostate Cancer UK now at an end, service users would normally have to pay in order to continue to access the service: holistic therapies and the gym are core elements of the HLC provision, and so will still be available as they are to other members of the public. The delivery team and the service users we spoke to thought that many existing users would pay to continue to come because they now recognised the benefits to their wellbeing. The local support group also thought that its own members who had accessed the service would continue to promote the service and its benefits to others.

While the holistic therapies will now have to be paid for by service users (about £15-20 per session), in the short term the gym will still be available free of charge thanks to the financial support of the Wirral and North Cheshire Prostate Cancer Support Group (covering the £2,50 per session fee). As one support

group official put it: “We wouldn’t want people to disappear for the sake of a couple of quid”. It is not known whether a fee would put people off from using the service, although a number of existing users come from deprived communities in the Ellesmere Port area, for whom finance might be an important consideration.

The delivery team is understandably disappointed that Prostate Cancer UK funding has ended after two years at a point, in their judgement, when the service had reached a point when it was beginning to run effectively and efficiently. They speculated that the same funding over a longer period would have been a more sustainable approach.

Michael's story

Michael (not his real name) was diagnosed with advanced prostate cancer in his fifties. He was searching for support to come to terms with his diagnosis, and to cope with the side effects of his hormone treatment, when he discovered a Pro-Active flyer in his local library and signed up for a group session.

Michael appreciated being able to decide which elements of the service to take up. He was not interested in trying acupuncture and, although he did try the gym, decided to continue to use his own nearer his home. His focus has been on the holistic therapies. He found the relaxation techniques very helpful and enjoyed the hands-on nature of the service, for example learning how to use pressure points on the scalp to release tension. The Indian head massage has been a particularly positive experience for him:

“I hadn't told anyone outside the family about my diagnosis, I felt incredibly tense...I was winding myself up into a frenzy. The massage really helped...the feeling an hour afterwards was absolutely magnificent...I feel it if I miss a week”

Michael has seen the benefits of the massage sessions on his mood, and his willingness to come to terms with his diagnosis:

“They make me much calmer. I'm not as worried...it sounds daft! I'm sleeping better, coping better with the emotional side of things...I came clean [about my diagnosis] and stuck it on by Facebook page. I'm amazed how many men don't really know about prostate cancer”

Michael recognises that holistic therapies may not suit all men. As a management professional, he considers himself to be more open to the potential benefits of such therapies, and of sharing problems with others. A couple of other men with prostate cancer who attended the group session could not see the benefits of positive visualisation or, in their words, “lying on the floor”, despite evidence of its success in high performing (male) sports like rugby and cycling.

Despite feeling well-disposed to the benefits of holistic therapies, Michael doesn't think that he would have accessed the service if it had not been free: “I don't think I would have considered it otherwise”. However, now that he appreciates the benefits, he will continue to use the service after the Prostate Cancer UK funding ends: “it's that good, I'm paying...I enjoy it too much”. He has also started to volunteer with Prostate Cancer UK as a way of giving something back.

John's story

John (not his real name) was diagnosed with prostate cancer 14 years ago. Having initially received radiotherapy, and cryotherapy after a recurrence of the cancer, he is currently on hormone therapy. Now in his seventies, John is an active member of his local prostate cancer support group, which meets at the HLC.

John's oncologist had encouraged him to take more exercise in order to help offset the muscle wastage that he might expect as a side effect of his hormone treatment. So, through Pro-Active, John and his wife have made use of the gym regularly once or twice a week. The gym does not provide any specific exercises or activity sessions for men with prostate cancer and their supporters, but Pro-Active provides access to the facility for free. The experience, John says, has been very positive:

"We've been thrilled with it...we have found it beneficial, as have other members of the support group"

John feels that he and his wife have got a lot out of the gym, both in terms of improving their general fitness, and in helping to relieve his constipation, which is a side-effect of his current medication.

"it's hard to tell the difference, because you do a little bit at a time...mentally, there's not a lot of difference...but it has kept us going. It's a benefit physically and a good discipline"

While Pro-Active kept John informed of the other services on offer, his busy schedule has meant that he cannot attend many other activities.

John and his wife intend to keep attending the gym after Pro-Active finishes, because they feel the benefit of regular physical exercise. He knows that other support group members have also found Pro-Active helpful, but that these are men who have already made the important decision to seek support:

"Those who come along to the support group will already have a positive attitude towards their cancer and wellbeing. It's the folks who don't come who are in the most need...but they've got to take the first step"

Supporting men with advanced prostate cancer

The George Thomas Hospice in Cardiff ran one day educational events for men with advanced prostate cancer and their supporters, followed by a range of one-to-one support sessions. Men said that it helped them to manage their pain and fatigue; reduce their stress and anxiety; and allowed them to share experiences and stories with other men with advanced prostate cancer.

The service

Prostate Cancer UK wanted to develop services for men with advanced prostate cancer; research suggested that this group were not receiving enough support to live with their diagnosis in advance of the palliative stage of the disease (which, for some men, can be quite a long time). George Thomas Hospice in Cardiff already had experience of supporting men with advanced prostate cancer through their existing work and they were keen to help set up what was an entirely new type of service to them. The service was designed by the two organisations working together.

Men with prostate cancer and their supporters were invited to one of five educational days held at the hospice. They were provided with information on their cancer; managing fatigue and pain; coping with incontinence and erectile dysfunction; and ways of relaxing and reducing stress. Information was given through a series of informal talks, followed by an opportunity to have additional one-to-one sessions. These covered a range of subjects including counselling, complementary therapies (like reflexology and Tai Chi), welfare/benefits advice, and diet. Men were also given books and other materials provided by Prostate Cancer UK to take home.

Demand for the service was good (46 of the 50 places were filled), with the majority of men coming to the service via their GP.

The benefits

Men benefited in a range of ways from the service:

- Peer support: being able to share experiences and stories with other people affected by advanced prostate cancer
- Practical solutions: some men were able to get financial support through welfare benefits; others received mobility aids to help them continue to live independently

- Relaxation and stress relief: complementary therapies allowed men (and their partners) to relax and reduce the stress related to their diagnosis and the side-effects of treatment, like pain. Counselling helped to address their psychological and emotional stress. Over 70% of service users reported reduced anxiety and stress
- Self-management: three-quarters of men said that the service had helped them to help themselves, particularly with pain and fatigue management

The service also helped men to discuss and address sensitive issues like incontinence and erectile dysfunction. In both cases, many men had not been aware of the developments in technology in these fields until they came to the education day.

What worked well

The hospice said that Prostate Cancer UK was very supportive and approachable in the development and running of this service. A regional point of contact (the Wales CSS Manager) helped because they could meet and discuss how the service was performing and how it might be improved.

GPs were a good source of men who went on to use the service, and the numbers coming from this route highlighted how many men in the South Wales community are living with advanced prostate cancer. Recommendations or referrals from medical professionals are a good way of encouraging men to take part in these types of service.

The service showed a lot of people that hospices can provide a wide range of support to people with advanced cancer, and are not just about palliative care.

What could have been better

The term 'advanced cancer' can be misinterpreted. A small number of men were directed to the service who did not have advanced prostate cancer.

It was hard to get service users to complete evaluation forms and questionnaires, so the benefits of the service are not as well-evidenced as they might have been.

Outputs

The service delivered close to its expected outputs. A reduced number of one-to-one sessions for men was more than made up for by the unexpected higher demand from men's supporters. A total of 50 men and 48 partners/supporters were invited to the education days, of whom 28 men and 18 supporters (46 in all) attended.

Output performance

Output	Target	Actual	Variance
Number of one-to-one support sessions delivered to men	240	225	-15
Number of one-to-one support sessions delivered to partners/ carers	90	136	46
Number of education programmes run throughout the year	5	5	0
Number of men reached through group education sessions	150	140	-10

Source: Prostate Cancer UK quarterly provider monitoring reports

Management and monitoring

The service team struggled with completing Prostate Cancer UK's monitoring requirements and getting feedback on outcomes and benefits from service users. The service tried to use the Support Team Assessment Schedule (a tool to assess the outcomes of palliative care) and the Hospital Anxiety and Depression to measure change before and after a man had used the service. But men were reluctant to complete the questionnaires and found them too medical-focussed. This was particularly the case with men who had not previously been hospice patients. The service would focus on collecting individual stories or case studies to monitor outcomes if they ran the project again.

Those outcomes that were recorded are set out in the table below. We understand that the lower than expected numbers is more due to the challenges of collecting outcome data than it is a comment on the value of the service.

Outcome performance

Outcome	Target	Actual	Variance
Improved cancer fatigue management	30	21	-9
Improved general wellbeing – reduced anxiety and stress	45	33	-12
Improved pain management	30	21	-9
Improved patients knowledge of their disease and self-management techniques	30	21	-9

Source: Prostate Cancer UK quarterly provider monitoring reports

Value for money

Budget suitability

The hospice said that the service was properly funded. The service manager found herself stretched by the need to oversee the service alongside her other responsibilities, and would delegate the role to someone else if the service ran again.

The service offered some people more one-to-one appointments than they were technically entitled to, but they felt in some cases that it would be wrong to cut off support suddenly to certain individuals. This was un-costed service provision.

Cost-efficiency

Actual expenditure (total and breakdown by activity) is not available for this service, so we are using the original budget of £10,992 to estimate cost efficiencies. Overall, the service has cost £239 per participant to deliver. This is slightly higher than expectation (£220) due to the slightly lower number of people using the service. We are not able to split the delivery costs between the education events and the one-to-one sessions. If we assume that the cost has all been absorbed by the one-to-one sessions, then the cost per participant per session is in the region of £30. The actual cost would be lower (accounting for the cost of the education events), and we would expect the costs to vary considerably depending on the type of session (e.g. group Tai Chi vs. individual counselling). So it is not possible to make any precise judgement about the service's cost-efficiency.

Cost savings

There is no detailed information on cost savings, but the service has identified two areas where savings might be made:

- A reduction in falls and associated medical treatment as a result of occupational therapist home visits and the offer of mobility aids to help people get around more safely and live independently
- Anecdotal feedback from GPs who said that their prostate cancer patients needed fewer appointments because of the help they were getting from the hospice

The service is also likely to have cost the public sector money where men were able to access welfare benefits (and mobility aids on prescription) where they might not otherwise have known they were eligible.

Future funding and delivery

Without additional funding from Prostate Cancer UK, the service has had to end. The services offered by this initiative are still being provided to the hospice's own patients but, without extra finance, it's not possible to continue to serve the wider population of men with advanced prostate cancer in the Cardiff area.

Brian and Mary's story

Brian and Mary (not their real names) are a married couple who live in Cardiff. Brian was referred to the advanced prostate cancer service at the George Thomas Hospice by his doctor in mid-2014. He had been going through a particularly difficult patch with his prostate cancer and his doctor thought he would appreciate some extra help. Brian and Mary had heard about the hospice before, but didn't really know much about what it offered. Mary in particular was worried about what a hospice might be like, and how suitable it might be for her husband; but in reality, it was not a problem.

They didn't know what to expect from the education day, but were keen to find out more about living with advanced prostate cancer; Brian had not previously received much non-clinical help or information from doctors and hospital staff.

Through the service, Brian has learned a lot about pain control, especially the pain associated with radiotherapy treatment. He also appreciated being able to talk to other men with advanced prostate cancer:

"It's interesting to meet people in your own position"

The couple both enrolled for reflexology sessions through the service and, after the six on offer, have decided to continue in the longer term. They both find the therapy "really relaxing" and would consider paying for the service in future, such is the benefit they feel.

The service has helped in more practical ways too. As a result of the service referring them to social services, they now receive an attendance allowance and have a blue disabled badge for their car. The hospice has also arranged for Brian's medication to be delivered to his home.

Brian and Mary described the service as "excellent", providing a good balance between offering information about living with the disease and some 'time out' to relax and forget about it for a while. It has allowed them to contemplate planning a holiday in the future, something which they didn't think would be possible before they used the service.

Tackling emotional problems through counselling

Local Relate organisations in different parts of the country gave personal counselling to people affected by prostate cancer: men, their partners and families. Men said that the counselling helped them to come to terms with a range of issues, not all of which were directly related to their diagnosis and treatment, and reduced their feelings of anxiety and depression as a result.

The service

Relate is a leading provider of counselling support in the UK which runs as a national network of individual organisations. Prostate Cancer UK funded several local Relates in different parts of the country to provide counselling to people affected by prostate cancer. This report considers the service provided by four local Relate organisations: Brighton, Hove, Eastbourne, Worthing and Districts; Birmingham; Greater Manchester North; and Greater Manchester South.

Counselling is known to help people cope with serious illness and its consequences. This service offered people affected by prostate cancer up to ten free counselling sessions – alone or with their partners/families – to help them address any personal, sexual or emotional issues they might have, such as coming to terms with a cancer diagnosis, managing money, loss of sexual function after cancer treatment, or help with relationship problems. Prostate Cancer UK gave some Relate staff training so that they could understand what the disease and its treatment meant to people affected by it. The charity also contributed to some training costs for new counsellors.

Demand for the service was slow to grow for all four organisations. In response, they all put more effort into promoting the service to other organisations working with and supporting people affected by prostate cancer, and numbers did increase just before the service ended. But the service did not reach the number of people it originally expected to (115 instead of 220). As a result, the service ran fewer counselling sessions than planned (505 instead of 695).

Relate, and other people who work with men affected by prostate cancer, think that men might have been reluctant to come forward for help with emotional and sexual issues, and were less aware of the potential benefits of talking to someone about their problems. It may be even more difficult for older men who grew up at a time when men were expected to be strong and silent. These factors may help to account for the low service take-up. In practice, men's partners were more likely to make the first contact.

The service expected to help men with psychosexual problems, because of the side-effects of some prostate cancer treatments, but in practice few presented with these issues or asked for support in this area.

The benefits

Counselling helped men and their families to discuss and address a wide range of issues including depression, anxiety, fear, domestic violence, and relationship problems. Some issues were in direct response to a prostate cancer diagnosis or its treatment; others were longer-standing problems that were brought into sharper focus after cancer was diagnosed.

Men said that counselling helped them to come to terms with their cancer diagnosis and the impact it had on their lives. It allowed them to talk through their feelings and fears, and begin to focus more positively on their future.

Men and their partners and families found difficult issues easier to talk about after counselling.

Most men said that they had less anxiety or depression after getting counselling.

What worked well

The service really helped men and their families address a wide range of personal and relationship issues.

Prostate Cancer UK's training for counsellors helped them to understand the disease, and the side effects of treatment, allowing them to provide appropriate support.

One service in particular overcame the problem of low numbers by identifying a lead member of staff to intensively develop partnerships in local prostate cancer networks

What could have been better

The service's challenges have all been about reaching men with prostate cancer and encouraging them to access the service:

- Relate's traditional profile, as an organisation helping couples with their relationships, meant that it was not always seen as a natural source of support by men looking for help to deal with their prostate cancer
- The relationship between a cancer diagnosis and the offer of personal counselling is not an obvious one
- Relate did not have a ready network of contacts to help with promoting the service, especially among local support groups
- Relate is traditionally a service provider, not a service promoter: the marketing and networking did not always come naturally

Earlier recognition of these issues, including more support and guidance from Prostate Cancer UK, might have helped to improve take-up of the service.

Funding from Prostate Cancer UK was too short term, given that the number of people using the service was just beginning to rise as the service ended. The local Relate organisations observed a lag of several months between their promotion activities and enquiries about the service, so a longer lead time would be an important part of any similar service in future.

Outputs

The numbers of people using the service grew over time, but fewer people accessed counselling than had been expected, as the table shows. The number of participants is about half the expected volumes, and this has resulted a reduction in the number of counselling sessions of more than a quarter.

Output performance

Outputs	Target	Actual	Variance
One-to-one sessions	695	505	-190
Men with prostate cancer receiving support	104	62	-42
Family members receiving support	116	53	-63

Source: Prostate Cancer UK quarterly provider monitoring reports

Management and monitoring

Relate has its own management and monitoring process, which it extended to this service. The additional monitoring requirements for Prostate Cancer UK were not significant. Relate's counsellors recorded their own notes from counselling sessions. They also trialled the use of questionnaires to measure anxiety and depression (the Hospital Anxiety and Depression Scale, PHQ-9, and GADS-7). Feedback from some men suggests that they were reluctant to fill in the questionnaire (which asks some very direct questions about how a person is feeling/coping), and on reflection Relate thinks that it is not a particularly good measure of counselling results, which tend to be very specific to the individual client.

The results from monitoring client outcomes are set out below. They show that the service broadly achieved its target numbers, but significantly overachieved when the figures are considered as a proportion of all men with prostate cancer who used the service. In five of the six categories, more than three-quarters of men reported a benefit (sexual function figures might be expected to be lower as it was less of an issue for men than first anticipated).

Outcome performance

Outcomes	Target	Actual	Variance	Proportion of men (target)
Reduced anxiety	47	49	+2	79% (56%)
Reduced depression	46	52	+6	84% (44%)
Acceptance of situation/outcomes	58	49	-9	79% (56%)
Able to manage expectations	48	53	+5	85% (46%)
Improved relationships	73	52	-21	84% (70%)
Satisfaction with sexual function	37	28	-9	45% (36%)

Source: Prostate Cancer UK quarterly provider monitoring reports

Value for money

Budget suitability

Some of the services underspent because of the lower user numbers. Most of the funding was for counselling sessions themselves. Marketing budgets tended only to cover the cost of printed materials. In hindsight, this was not enough given the efforts needed to reach men with prostate cancer and

encourage them to take up the service. The budget did not cover the cost of staff who had to go out and promote the service with clinics and prostate cancer support groups. This was a significant amount of additional effort and resource for small organisations not configured to take on this networking role.

Cost-efficiency

Due to a lack of information, cost efficiency is based on the planned budget for the four services (£41,145), rather than the actual expenditure. Based on this figure, the cost of delivering the service was £358 per person, or £89 per session (including marketing and training costs). This is higher than the original budget because user numbers and sessions were lower than planned (the expectation was £187 per person, or £59 per session).

Relate normally asks its clients to provide a donation to cover the cost of counselling, so there is no fixed price for the service to allow a direct comparison. The cost of personal and relationship counselling provided by other organisations varies widely within a range of about £25 - £80 per session. So the Relate service would have fit into this range had it delivered the anticipated volumes of delivery. As it did not, the service was quite expensive on a 'per session' basis.

Cost savings

Relate thinks that the emotional and psychological benefits to people attending counselling might result in them making fewer visits to see their doctors (for example, by reducing depression). By keeping families together, the service may also have reduced the burden on other parts of the public sector, such as social services. But there is no concrete evidence to support these suggestions.

Future funding and delivery

Prostate Cancer UK funding for the service has now ended. People affected by prostate cancer can still get counselling but it is no longer free or being specifically promoted to them. A small number of men continue to receive counselling on a paid basis, which suggests that they are still benefiting from the support they receive.

Relate will still be able to benefit from the training and experience it has gained from working with Prostate Cancer UK and those affected by the disease if and when it works with people with cancer. Relate thinks that the experience will help them support people with other cancers and life-limiting illnesses.

How counselling has helped

Two of Relate's counsellors talked about why men needed counselling, and what they got out of it.

Overcoming the initial shock of a prostate cancer diagnosis: clinicians can be quite blunt and factual when telling someone that they have cancer. Counselling has helped some men to get over that shock and come to terms with their diagnosis:

"It's a lot about processing that initial shock, and then how they move on. It's a lot to think about, and brings on fear, anger and stress"

Managing the side-effects of treatment: the treatments for prostate cancer can change men physically, and how they view themselves. It can also be intrusive. For some men, treatment is not the end of the story:

"Men have feelings of loss of control, not knowing about the future. They say "I haven't been ill up to now", "why me?", "what have I done to deserve this?" There is a sense of being punished. Managing changes [brought about by cancer treatment] is quite different to what they have experienced with their health in the past"

Help with expressing feelings: men are not always very good at expressing feelings, something that can get in the way of coping with cancer:

"Men sometimes expect to fix the problem rather than addressing their feelings around the disease. Once those feelings have been expressed and heard they don't seem as shocking or scary. This helps them to manage the disease, to see through the mist of their feelings, and feel more empowered."

"I was hearing positive signs about them seeing the future – talking about the future, seeing what they could do, what their hopes are, which I think is a sign of them feeling less overpowered by their feelings."

Supporting relationships: prostate cancer can put additional strain on a couple's relationship, and counselling can help to encourage dialogue between the man with prostate cancer and his partner.

"The ones who come as couples find they are able to talk...a counsellor can ask how they felt when they heard the diagnosis...they come back saying they are able to talk now; things are not unspeakable"

Simon's story

Simon is a married man in his forties who was diagnosed with prostate cancer in mid-2014. The cancer was found quite by accident, and a prostatectomy followed soon after. He quickly recovered from the physical side-effects of the treatment, but the emotional recovery took longer. He became very tearful several months after his treatment while raising money for Movember, and small events would cause him to cry. He began to realise that he had not taken time to fully process the shock of what he had gone through earlier in the year.

His first thought was to approach a prostate cancer support group, but the groups local to him catered for a much older age group (over sixty):

“It was not a supportive structure for someone of my age”

He then contacted his GP who put him in touch with the Relate service. It was not an organisation he would have naturally thought of to help him with his concerns:

“You always think of Relate when your marriage is on the rocks...but I wanted an independent individual I could speak to; not a relative”

Simon is an open-minded, reflective person. Counselling suited him well and he liked the informal, organic approach of his counsellor:

“It seemed natural, the conversation evolved”

He attended his full eight counselling sessions, using them to talk about his emotions and what he had been through. His counsellor also gave him some advice on coping strategies, like mindfulness.

“She confirmed that what I went through was a natural reaction...now if I feel tearful, I just cry – it's best to get the emotions out. I was giving myself too much of a hard time”

Simon's counsellor was also a sex therapist but he never felt the need to pursue that area of his life. His wife attended one session, but the support provided by the service was primarily focused on his own needs. He recommends the service:

“This is a very good service for men of a similar age as myself”

Patrick's story

Patrick is a gay man who was diagnosed with prostate cancer seven years ago and is now on active surveillance. He was contacted through a support group by his local Relate, which was looking to boost the number of people using the service by promoting it directly to individuals. While he was not actively looking for emotional support, Patrick realised that might need help:

"I knew I needed something. I got upset easily, I was getting angry and short-tempered...but men are designed not to ask for help, it's hard-wired in us. Being a man gets in the way of being a man with prostate cancer"

His expectations of the service were quite low, assuming that Relate might not be the right organisation to help him:

"I thought: Relate – don't they do middle-aged couples with marriage problems?"

Despite his reservations, the sessions went well and the process worked for him:

"I had stuff in my head and I needed to get it out; to get intelligent feedback. I was making sense of it, and the counsellor was reflecting it back. That's what helped me in my sessions"

Over the course of about seven sessions, Patrick was able to talk through a number of different issues, not all of which were directly related to his cancer:

"Sometimes having prostate cancer uncovers things which have been there for a long time. Sometimes it's a catalyst"

"Now I don't choose partners on the basis of whether they will want to know about my prostate cancer. Now I talk things through with them, I can better articulate it to others"

"My personality is to look after people, and I tend not to look after myself and that's where I needed Relate"

While he recognises that he personally benefited from the service, Patrick is not sure how suitable it would be for other gay men:

"It still felt a little bit like what I thought old Relate was like. It's very much 'this is the way we do it'. It's not likely to be attractive to the gay guys I know. You [the counsellor] are not gay, you're not a man"

Helping men to stay on active surveillance

Guy's and St Thomas' Hospital ran seminars on active surveillance for men with prostate cancer. The group sessions, which covered clinical information and provided help with men's wider wellbeing, helped to reduce the number of men dropping out of the active surveillance programme.

The service

For several years, Guy's and St Thomas' Hospital had been running group support and information sessions for some of its prostate cancer patients. Their research showed that, given this support, fewer patients called the clinic with concerns; they were keeping in touch with, and helping one another; and men generally felt better supported compared to receiving traditional one-to-one support.

The hospital noticed that men on active surveillance (a way of monitoring prostate cancer rather than treating it straight away) didn't feel well supported, and many dropped out of the surveillance programme. This was backed up by academic research showing that up to one third of men dropped out of similar programmes, half within three months - some men struggle to come to terms with living with cancer without it being immediately treated.

With funding from Prostate Cancer UK, Guy's was able to extend its group support approach to men on active surveillance (and their supporters), with the aim of keeping more of them on the programme. The programme involved running seminars for men explaining active surveillance plans and medical issues (such as biopsies) as well as providing wider wellbeing advice, such as relaxation techniques. The seminars were developed with the help of men with prostate cancer to make sure it suited their needs. Men were required to opt out of the seminars, rather than opt in, in the expectation that men would be more likely to attend if their clinician told them it was part of their overall treatment.

Due to staff changes, the service has not yet completed all of its seminars. It has so far supported 135 men and 70 of their supporters (partners, wives, etc.).

The benefits

Everyone who took part – men with prostate cancer and their supporters – improved their understanding of active surveillance as a way of being treated for prostate cancer.

More men are staying on active surveillance. In its first year, the service helped to cut the number of men dropping out by 10%.



What worked well

Prostate Cancer UK did not have to provide support beyond the funding as the hospital is a leading centre for urology and had used a similar seminar process with men having different prostate cancer treatments.

Men seemed to like getting information and advice in a group of their peers.

Attendance has been high. Delivering the service in a clinical setting, and with the 'opt-out' approach, helped to encourage men to attend.

The service successfully targeted black men in the population, who traditionally are harder to engage about prostate cancer.

What could have been better

Staff changes mean that the service has not yet completed all of its seminars.

Outputs

The service has not yet delivered all of its seminars because of staff changes. So far, half of the seminars have been delivered. At 40 people per seminar, numbers are in line with expectation, as is the balance of attendees between men with prostate cancer and their supporters.

Output performance

Outputs	Target	Actual	Variance
Active surveillance seminars	10	5	-5
Men attending the seminars	250	135	-115
Supporters attending the seminars	150	70	-80

Source: Prostate Cancer UK quarterly provider monitoring reports

The service successfully reached out to black men, who are more likely to get prostate cancer than other men. Guy's and St Thomas's is also located in an area of London with a very large black population. Black men represented one third of the men who attended the seminars, a bigger proportion than in the local community (26% of residents in Lambeth and Southwark were black according to the 2011 census).

Management and monitoring

The service team was comfortable with the levels of monitoring required by Prostate Cancer UK. The two main outcomes they chose to measure were quite easy to monitor, firstly whether men and their supporters improved their knowledge of active surveillance (100% success to date) and, second, whether men stayed on their active surveillance programme (clinical audit shows a 10% reduction in drop-outs).

Value for money

Budget suitability

The service team thought that the budget for the service was suitable. The service had been running for a year before this current contract started, which gave them an opportunity to understand what the real costs of delivery would be.

Cost-efficiency

Assuming that the service completes its seminars with the same attendance figures as it has achieved already, the seminars will have cost £360 each, at a rate of £9 per person. This is a very low cost to Prostate Cancer UK, although it should be remembered that the charity is not covering the costs of the medical staff who attend the seminar.

Cost savings

Specific cost savings have not been identified by the service, but there are possible savings to be made in three areas:

- A reduction in staff costs by seeing men with prostate cancer in groups, rather than individually. The team are hopeful that a case can be made for the hospital to continue funding the service on the basis of these savings
- A reduction in staff costs because men are more comfortable with being on active surveillance, and so make fewer appointments to see their doctor or specialist with worries or concerns
- A reduction in treatment costs if more men decide to stay on active surveillance. Academic research indicates that active surveillance is more cost-effective for up to ten years compared to early alternative treatments for men with low-risk prostate cancer.

Future funding and delivery

Prostate Cancer UK will not be providing further funding for the service, but its success means that the team at Guy's and St Thomas' are hopeful that it will continue as part of the hospital's normal service to active surveillance prostate cancer patients.

Improving the cancer journey with Holistic Needs Assessments

The service provided holistic needs assessments (covering mental health, housing, physical health, welfare benefits etc.) to men with prostate cancer and their supporters in Glasgow. The service helped to relieve the stress and anxiety associated with living with prostate cancer as well as offering practical support by referring people to other agencies and services.

The service

The Improving the Cancer Journey service was set up by Glasgow City Council, Macmillan Cancer Support and other agencies. They recognised that people living with cancer are affected in many more ways by the disease than their health alone, such as housing, money problems, or emotional issues.

The service employs link workers who carry out holistic needs assessments – a process of gathering information about a patient, medical and non-medical, including their social, financial and emotional needs. The link workers act as a single point of contact for the individual, helping out, signposting or referring them on to other specialist forms of support depending on their particular needs.

Funding from Prostate Cancer UK enabled the service to be expanded and for the link workers to be trained specifically in the support needs of men with prostate cancer. It also enabled more men to be seen, and more quickly. Over half of the men seen by link workers had issues with money, housing or other non-medical concerns where they needed extra help.

The service operates through local libraries and other community centres.

74 men with prostate cancer were supported by the service, 69 of whom had concerns or issues for the service to help them with.

The benefits

Men said that the service helped them to address a range of non-medical concerns. The most common issues were mental health, anger, frustration, anxiety, and depression. Men said that they found it easier to manage anxiety and other stress-related conditions as a result of the help provided by the service.

Men said that they felt less isolated. The meetings with their link workers and other support organisations got them out of the house and allowed them to remain part of their local community.

What worked well

Prostate Cancer UK was able to influence an existing service for all cancer patients in Glasgow and make it more relevant to men with prostate cancer. Link workers were trained by Prostate Cancer UK to understand what issues and problems men might face. The resources provided by Prostate Cancer UK were well received by link workers and their clients.

The referral system worked well. The NHS would refer men to the service, and meetings were arranged quickly.

Men liked to know that they could contact their link worker at any time if they had concerns, and didn't have to wait until their next appointment.

Link workers and their clients thought that the different organisations working through the service communicated well and the process of referring people between them was smooth.

The information gathered by the service provides a very rich picture of the challenges facing men with prostate cancer, and this should help the future development of other support services in future.

The service successfully helped men from the most socially and economically disadvantaged communities; they often have the greatest need for help, but cannot or will not access it. More than half of the service's clients came from this group.

What could have been better

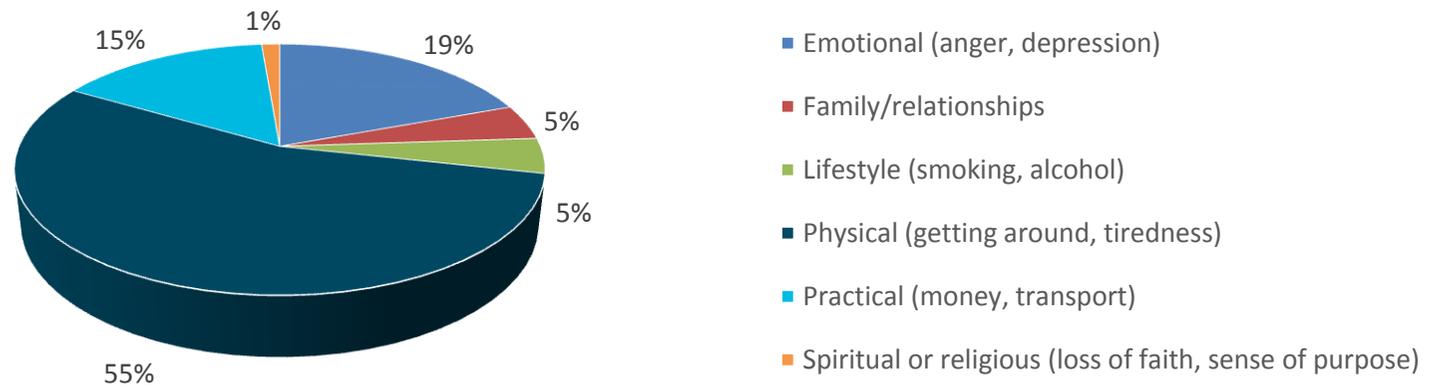
Some men, and the service itself, thought that there could be more support for issues relating to sexual function and sexual identity. Some men felt that this wasn't properly addressed in their clinical appointments and that they would appreciate more help.

Short term funding stops Prostate Cancer UK from making the most of relationships with other organisations that take time to establish, and then cannot be maintained because of the limited timescale.

Outputs

No specific targets were set for the service. Over 15 months of operation, the service received 74 prostate cancer clients, of whom 69 had concerns requiring support. Nearly two thirds of the clients were referred to the service by their GP or another healthcare professional; 42 lived in the most disadvantaged areas of Glasgow.

On average, each client registered 10 concerns (the maximum for one client was 30). The chart below shows that physical concerns were the most common.



Those requiring help with their finances received an average of £1,748 in welfare benefits each (23 clients).

The largest number of referrals were made to various schemes and services provided by Macmillan. Nearly 10% were referred to other Prostate Cancer UK services. Three quarters of those who were referred to another agency or service attended their appointment.

More than three-quarters (78%) of men said that they were very satisfied with the service; only 2% were not satisfied.

Management and monitoring

The process for managing and monitoring the Prostate Cancer UK element of the service was straightforward and easy to implement. Glasgow City Council had a service level agreement with Prostate Cancer UK which outlined the requirements of the funding. The service team used mobile working devices to easily record client outcomes, outputs and consultation notes.

Value for money

Budget suitability

The service team felt that the funding received from Prostate Cancer UK was appropriate to support the planned work. The budget funded a partial restructure of the team which enabled more link workers to respond to men's needs. The funding also supported the training of link workers to ensure they understood the specific needs of men with prostate cancer.

Cost-efficiency

Cost-efficiency calculations are difficult to make as Improving the Cancer Journey as a whole is a £3.5m project, of which Prostate Cancer UK are only contributing £35,000 (1%). It is likely that not all the costs of delivering the service to prostate cancer patients are being borne by Prostate Cancer UK, but that the funding has helped to improve the service to these men, and ensure that their profile and needs are raised within the service as a whole.

Based on the Prostate Cancer UK funding alone, the cost of delivery averaged £507 per person, or £78 per link worker appointment (this figure excludes informal contact between appointments).

The cost of delivery (again, just Prostate Cancer UK funding) seems good value for money when compared to the salary and workload of a junior social worker (link workers were primarily recruited from the social work sector). Based on the average salary and caseload of a social worker, the service might need to pay in the region of £50,000 to manage a similar number of clients. This is a very approximate calculation, and much depends on the amount of time and effort required to support an individual client.

Cost savings

The service delivery team thinks that the service has the potential to save the health and social care system money by improving the wellbeing of prostate cancer patients and their supporters, and thereby reducing their likelihood of developing depression, anxiety and similar mental health issues that would

require medical treatment. In addition they believe that the simple referral process between partners, partly due to co-locating services, saves time and money in delivery and makes the system more user-friendly. However, there is no evidence to confirm that this has actually been the case.

In other areas of activity, the service may actually increase costs to the public sector where it helps men with prostate cancer to access other services and benefits (e.g. helping to secure welfare payments that they would otherwise not have claimed).

Future funding and delivery

The service will continue in Glasgow although without additional funding from Prostate Cancer UK. In order to support men with prostate cancer at the same level in the longer term, there will be a need for ongoing training for the link workers as treatments and support needs change (and staff move on). Currently there are no concrete funding sources that can support this.

As part of this service the team is looking to develop a Scottish Vocational Qualification (SVQ) to support link workers and other staff involved in future delivery.

John's story

John (not his real name) was diagnosed with prostate cancer 3 years ago. The initial outlook for John was positive with treatment being focused on hormone therapy although he did also receive radiotherapy following diagnosis. John was in his early sixties when diagnosed and initially struggled to come to terms with how the cancer would impact on his life.

John was invited to be involved in the Improving the Cancer Journey service by his doctor and he made an appointment to see a link worker at his local library. The Holistic Needs Assessment identified a number of concerns and areas where John felt he was struggling. Since his treatment John has felt embarrassed to go out into town, a trip he used to make regularly. John was worried that he might not be able to find a toilet quickly or easily and this anxiety led him to staying at home more and more. He talked to his link worker who arranged for him to have access to a Radar Key. This allowed John to access the range of toilet facilities in the city, making trips into the city an option again:

“I never knew I would even be entitled to access a Radar Key. With the support of my link worker I now feel more comfortable going out and about to do shopping and visit friends as I know I now have easy access to public toilets. It was a weight off my mind”

John feels that he has got a lot out of the service, both in terms of improving his general wellbeing, and in helping to reduce his anxiety levels. He found that he often got angry in the early stages of his treatment and this caused problems both at home and with his friends:

“The help I got to address my anger has made a real difference. Being diagnosed with cancer was very isolating for me and I bottled most of my feelings up. My family had to bear the brunt of this and it was only through the anger management course my link worker talked to me about did I manage to express my feelings better and reduce my stress. It has made a real difference”

John is intending to keep in touch with his link worker and keep using the techniques he has used, as well as his Radar Key. He hopes that other people will be able to use the service in the future and is now much happier talking to people about his cancer and to help others in similar situations:

“The support offered has really changed my outlook. I feel more positive about the future and I know if I have any other concerns I can pick up the phone and get them sorted out quickly. I know I am no longer alone”

Social prescribing to help men with prostate cancer

Age UK Northumberland ran a telephone service for people affected by prostate cancer, providing them with access to a range of non-medical support linked to their prostate cancer or its treatment. As a result, men improved their sense of wellbeing, and felt that their concerns and worries had been addressed.

The service

Prostate Cancer UK saw a need to help men with prostate cancer in Northumberland. A large, and mainly rural county, men had to travel a long way to see a specialist nurse and were missing out on non-medical forms of support to help them live with and beyond their cancer.

Age UK Northumberland already had experience of social prescribing: connecting people to non-medical sources of support provided by other services and organisations. With funding from Prostate Cancer UK, Age UK was able to raise awareness of prostate cancer in the county, and extend its existing telephone support service to people affected by prostate cancer. Men were referred into the service by their hospital, or could refer themselves. The service was free to use and allowed men to access a range of support including benefits, welfare and housing advice.

The benefits

All the men who used the service said that their wellbeing had improved as a result, but information is only available for 12 people.

Many men were referred on to other support services as a result of their contact with Age UK, including friendship programmes which helped to reduce men's sense of isolation.

More people and local community groups around the county are now aware of prostate cancer and the challenges it brings for people affected by the disease.

What worked well

The service was easy to set up as it used an existing model run by Age UK locally. The funding from Prostate Cancer UK enabled more people to be supported and to spread awareness of prostate cancer more widely. Prostate Cancer UK's resources were highly rated.

Men appreciated getting one-to-one advice which helped them to access a wider range of help and support. Most men had a higher number of contacts with the service than was originally planned, suggesting that they valued the service and/or had more needs than the service originally expected.

The service established relationships with the cancer specialist nursing team at the county hospitals as well as other healthcare professionals and networks of community groups.

What could have been better

The number of referrals to the service was much lower than planned despite changes being made to improve the flow of men accessing the service. A number of changes were made to the process but referrals remained low.

Referrals have continued to come in since Prostate Cancer UK stopped funding the service, suggesting it takes time for people to become familiar with the process (and for men to decide to seek help). If this is the case, the charity should consider a longer term funding strategy.

Outputs

The number of men using the service was much lower than originally planned: only one third of the target number accessed the service. This meant that the number of contacts with men (and their families) was lower too. However, the number of contacts per person was higher than planned: on average, each person using the service had six contacts, instead of the planned three. This might mean that their needs were greater, or more complex, than had been expected when the service started.

The service was more successful with its training and awareness-raising, exceeding both of its targets by a long way. Even with this higher volume of awareness-raising, the number of men using the service was low: one man used the service for every 489 people targeted, which is a lot of effort to put in for limited gain.

The main issue with referrals appears to have been with the hospitals, where initial enthusiasm for the project among healthcare professionals did not translate into the active encouragement of men to access the service despite the efforts of Age UK to improve the situation. The increased amount of

energy put into community awareness-raising reflects the charity's attempts to generate more self-referrals to fill the gap, although this and other similar services say that the main target group (older men) tend not to seek help by themselves, even when they need it. That's why the 'push' from clinicians can be so important.

Output performance

Outputs	Target	Actual	Variance
Prostate cancer training to be received by all managers/staff & volunteers	327	849	+522
Referral pathways from local hospitals established	3	3	0
Men and family members affected by prostate cancer referred to Age UK Northumberland	50+	17	-33
Number of contact support to men and families affected by prostate cancer	150	107	-43
Service users targeted in local communities around prostate cancer awareness	600-800	8318	+7,518
Individual case studies	8	2	-6

Source: Prostate Cancer UK quarterly provider monitoring reports

Management and monitoring

The service delivery team found Prostate Cancer UK's monitoring requirements straightforward although they felt that they could be time consuming and required a greater level of management input than they had expected. They used the MYCAW questionnaire as a means of quantifying the benefits of the service to its users. Although not all targets were met this was in part due to the low number of referrals onto the programme and not the quality of the service provided (see table overleaf).

The service used the MYCAW (Measure Yourself Concerns and Wellbeing) questionnaire to assess changes in service users' anxiety and wellbeing. Only 12 were completed, but all showed an increase in overall wellbeing, and a reduction in concern for the issues that mattered most to them. The full results are provided in the table below, but the percentages are based on very small numbers.

Outcome performance

Outcomes	Target	Actual	Variance
Increase in overall wellbeing	90%	100%	+10
Decrease in individuals identified number 1 concern	85%	100%	+15
Decrease in individuals identified number 2 concern	70%	100%	+30
Contacts referred to further support	50%	59%	+9
Contacts accessing more than one support service	50%	65%	+15
Contacts accessing benefits advice	50%	59%	+9

Source: Prostate Cancer UK quarterly provider monitoring reports

Value for money

Budget suitability

The service delivery team felt that the budget was appropriate for the nature of the provision being offered, although the amount of management time put into the service was more than expected. The Prostate Cancer UK money was spread between the benefits and housing advocacy services and this enabled them to provide more services for a longer period to both men with prostate cancer and other service users. The programme ran largely due to volunteer input which was crucial to its success.

Cost-efficiency

We only have a figure for the service's planned budget rather than its actual expenditure or expenditure headings, which limits our ability to comment on cost efficiency. The original budget was £26,000, and the service directly supported 17 individuals: a unit cost of £1,529 per person. However, this figure is a slightly unfair metric as the service put a lot of effort into raising awareness of prostate cancer within its wider voluntary and community networks; and training its staff and volunteers.

Cost savings

The service delivery team considers the Age UK programme has the potential to save the health and social care system money by improving the wellbeing of prostate cancer patients and their supporters, and thereby reducing their likelihood of developing depression, anxiety and similar mental health issues. However, there is no evidence to confirm that this has actually been the case.

Future funding and delivery

The service team felt that the project was only just getting going when the funding came to an end (although referral numbers actually declined over time). This was disappointing to the team given the considerable time and effort put into building new relationships with hospitals and other community organisations. Despite this, Age UK are committed to trying to deliver a service in the future without Prostate Cancer UK funding, even if that is only continuing a scaled down benefits and housing advocacy service.

The benefits for the organisations have outweighed any negatives and the service team feel that they have successfully raised the profile of both Age UK and prostate cancer. Age UK are considering whether a hospital-based welfare officer might be a more effective way of providing a social prescribing service, rather than relying on remote referrals from busy healthcare professionals.

Encouraging healthy living

The Healthy Living Programme comprised six workshops for men with prostate cancer and their partners or carers in Wakefield. The service supports men with different aspects of self-management including managing their symptoms, benefits advice, emotional wellbeing, diet and healthy eating, and exercise.

The service

The Healthy Living Programme was run by Age UK Wakefield in partnership with Wakefield Carers. The service built upon an existing Macmillan service that was run in the city but it was adapted, with the support of Prostate Cancer UK, to enable specific workshops to be run for men with prostate cancer and their partners or carers.

The programme was run three times over a twelve month period and each time six workshops were delivered covering a range of emotional and physical support needs. The sessions were run in local community settings and usually at the same venue over the course of the six workshops. Different providers and support staff presented at the workshops which were open to all men and their partners or carers. Each session involved an activity or presentation with an opportunity for informal conversation at the end.

The benefits

The biggest benefit to men and their partners was social. Most men said that the workshops helped them to recognise that they were not alone. Having their partners at the workshops helped men to open up and share experiences, often surprising themselves with their own openness in the process.

Most workshops were well attended and considered to be useful, especially the information regarding oncology support, exercise and erectile dysfunction. The groups bonded over the course of the programme which helped people to deal with their stress and anxiety. This led to a greater sense of wellbeing amongst the men as they could share experiences with each other.

Some men said that they would now do more exercise and make other changes to their lifestyle as a result of attending the programme.

What worked well

Establishing the programme was straightforward as it mirrored a previously run programme which was adapted to focus on the needs of men with prostate cancer. The partners had all worked together previously and were located in the same premises in Wakefield. This also made responding to the needs of services users easy as referrals between the partners could be undertaken quickly.

The majority of men who attended the programme felt that the structure, format and topics discussed worked well and they would recommend the programme to other men diagnosed with prostate cancer.

Some of the workshops were very popular including the session with the oncology nurse and the exercise session. The atmosphere at the workshops was considered to be encouraging and created a sense of community, both for the men and their partners/carers.

Establishing relationships with local cancer clinics helped to signpost men to the service. It also introduced clinicians to the services that could be offered by local voluntary and community services.

What could have been better

Some men felt that a workshop looking at incontinence earlier on in the series would have been more helpful because it was something that men were not good at preparing themselves for.

Despite efforts by the delivery team and invitations to attend, the service was not as successful with engaging black and minority ethnic men as it had hoped.

Outputs

The service set itself a target of 216 attendances by men with prostate cancer. We understand this to be 12 men per workshop, 6 workshops per session, 3 sessions (or 36 individual service users). The service slightly exceeded its attendance target (220). It expected an equal number of partners and carers to attend, but numbers were much smaller than expected (73). Physical activity sessions were also less popular than had been anticipated.

Output performance

Outputs	Target	Actual	Variance
Men with prostate cancer attending	216	220	+4
Partners/carers of men with prostate cancer attending	216	73	-143
Physical activity fortnightly sessions for prostate cancer patients	168	36	-132
One to one activity Leaf assessments and personal goal setting.	54	40	-14
Unique service users (men with prostate cancer/supporters)	36/36	42/14	+6 / -22

Source: Prostate Cancer UK quarterly provider monitoring reports

Management and monitoring

The outcome data for the service is rather complicated due to the use of proportions in the targets. We have assumed that the target numbers represent the proportion of unique service users expected to demonstrate the stated outcome, with a total target number of 72 participants. On that basis, the service has performed well across all those outcome areas where it reported evidence (see table overleaf – no figures were reported for three of the outcome areas).

Outcome performance

Outcomes	Target	Actual	Variance
Improved awareness and understanding of prostate cancer and managing symptoms	75%	93%	+18
Improved awareness of benefit entitlement and access to benefits advice & help	80%	95%	+15
Seeking further advice and support for benefit entitlement.	50%	59%	+9
Seeking further practical support from Age UK Wakefield services	60%	89%	+29
Increased knowledge of how to manage stress and anxiety	70%	95%	+25
Reporting a reduction in sense of feeling isolated	75%	-	-
Men going on to do 1-1 goal settings with Age UK Wakefield	50%	-	-
Men increasing physical activity through the Prostate Cancer UK and Age UK Wakefield programme	35%	-	-
Men reporting a positive impact on their physical and emotional health	50%	100%	+50

Source: Prostate Cancer UK quarterly provider monitoring reports

Value for money

Budget suitability

The delivery team thought that the budget was suitable for the workshop provision. Age UK was keen to ensure that only the minimum costs required were applied for and this resulted in 18 sessions being run over the year for a little under £11,700. This primarily paid for venue hire, speaker costs and refreshments for the men and their supporters.

Cost-efficiency

The programme would not have gone ahead without the support of Prostate Cancer UK. The workshops, although based on a previous model, were designed specifically to meet the needs of men with prostate cancer and their partners and carers. The budget was suitable and well managed and enabled

delivery of a cost effective service embedded within the community. This was important to the men who accessed the services. The cost per workshop and attendee were reasonable for the support offered and considering the potential benefits that were gained both by the men as well as the health service.

Cost per session/service user (actuals)

Service element	Number	Direct cost	Cost per workshop/service user	
			Direct costs only	Including overheads
Cost per workshop	18	£8,390	£466	£650
Cost per attendee on the programme, per workshop	293	£8,390	£29	£40

Source: Prostate Cancer UK quarterly provider monitoring reports

These figures compare favourably with similar commercial (and publicly-subsidised) services. To hire a community venue for half a day, cater for 30 people and to hire a speaker for two hours costs around £400 -700 depending on the venue, location and speaker. The overall cost per individual of £40 per workshop including overheads appears to be good value for money.

Cost savings

The service delivery team thinks that the programme has the potential to save the health and social care system money by improving the wellbeing of prostate cancer patients and their supporters, and thereby reducing their likelihood of developing depression, anxiety and similar mental health issues. However, there is no evidence to confirm that this has actually been the case.

Future funding and delivery

Age UK and Wakefield Carers, in partnership with the NHS, are keen to run the workshops again and appear to have secured funding from the Mid Yorkshire Hospital Trust to continue with the programme for another 12 months. Throughout, the service delivery team has sought to minimise costs in order to make the programme more attractive to new potential funders. They are considering whether some of the sessions could be delivered in hospital settings in the future as part of clinical pathways for patients, and whether a similar approach would work for people with other cancers or long term conditions.

Paul's story

Paul (not his real name) was diagnosed with prostate cancer two years ago. He was diagnosed early and received hormone therapy, but had to undergo more invasive treatments which resulted in him having to use a catheter and make changes to his lifestyle.

Paul received an invitation letter from the hospital which explained what the Healthy Living Programme was and how it might help him and his wife. He wasn't entirely sure whether he should attend on his own or have his wife attend with him.

"I was a little worried that if I took my wife along then it may prevent other men speaking up and talking about their cancer. I wouldn't know anyone there and wanted to see what it was like first"

Paul attended the first session and was immediately put at ease. Other men had invited their partners and carers along and contrary to what Paul thought the men did start opening up and talking freely about their conditions and any concerns they had. Paul spoke to his wife when he got home and agreed that she would come to the next session. His wife has attended all subsequent sessions and has found them beneficial. Paul noted that:

"The sessions themselves are useful and I've learnt about my condition but the most important aspect has been the sense of community here. The staff have been brilliant and everyone just gets along. It has been a great support, for both of us actually. I have got more out of the sessions than I thought I would and I hope to keep in touch with some of the other men and their wives"

Paul feels that he has got a lot out of the service, both in terms of improving his general wellbeing and this has been driven by the social elements of the workshops. He only had one suggestion for the future of the service:

"To be honest the whole catheter thing was quite a shock. It is hard to prepare for the way it changes your life and in the beginning all the little things seem to be so complicated, like where to get some pads. I think it would be helpful if they ran a session on catheter use and how it changes your life. Spend some time going through it with the guys, I think that would really help"

Paul may attend a follow up session in a few months just to see how everyone is doing. He regards it as having been an invaluable part of his treatment.

A whole-person approach to survivorship

Penny Brohn cancer charity ran group sessions for men with prostate cancer and their supporters focussing on helping them to live with and through their cancer. The service, which provided emotional, physical and psychological support, helped men to improve their capacity for self-management.

The service

Penny Brohn is a charity that takes a whole-person, patient-centred approach to living with cancer. It aims to help people affected by cancer by providing emotional, physical and psychological support alongside their medical treatment.

Penny Brohn has traditionally supported people with other cancers, such as breast cancer, and both they and Prostate Cancer UK thought that the approach would also work for people affected by prostate cancer (men, and also their partners). Prostate Cancer UK also felt that there was a gap in survivorship support: help for men to live with and beyond their cancer and its treatment.

Prostate Cancer UK funding allowed Penny Brohn to tailor two of its established services to the needs of people affected by prostate cancer and deliver them in several locations around the country (this report looks at the service in Leicestershire and at Barts Hospital in London). They worked with specialists to include subjects specific to prostate cancer including erectile dysfunction, incontinence, and the side effects of certain treatments like hormone therapy.

The two services were:

- Health and Wellbeing Clinics: half-day, group events providing clinical advice, an opportunity for group discussion, and access to other information and support in the form of a 'market place' – stalls from various groups who support men with prostate cancer providing advice on things like diet and exercise, and offering counselling. Men were encouraged to go by their clinicians, rather than it being offered as an option. Four clinics were delivered in London and Leicestershire attracting 75 participants, which was lower than the expected 102
- Living Well Course: a three-day course that is something of a natural extension of the Health and Wellbeing clinics, where smaller groups of men and their partners receive more in-depth support, including relaxation techniques, mindfulness, meditation and goal-setting. The course was promoted on an 'opt-in' basis and was delivered once in London. Eleven of the twelve places on the course were taken up.

The benefits

Men and their partners benefited in a range of ways, reflecting the breadth of support mechanisms provided by the service. This included help with diet, physical activity, relationships, and self-management of their condition more generally.

Significant individual benefits included addressing claustrophobia which helped one man to use an MRI scanner for the first time.

Informal feedback from doctors whose patients used the service shows that they learned a lot from the experience and felt better supported as a result.

Group working was widely welcomed. Men found it really helpful to be able to meet and talk to others with prostate cancer. Having other men in the room helped to ensure that important questions, however awkward or embarrassing, were asked by at least one man.

What worked well

Men seemed more likely to attend when told to by their doctors (as was the case for the Health and Wellbeing clinics) rather than it being offered as an optional extra to their clinical treatment. One healthcare professional described men's approach as "if you tell me what to do, I'll do it".

Presentations were adapted to ensure that they were culturally relevant to local communities.

The involvement of a health professional, funded by Prostate Cancer UK helped to encourage other clinicians to refer their patients to the service. Her wider network of contacts also helped to bring a range of support organisations to the Health and Wellbeing clinics in London. She also provided an element of 'quality assurance' in terms of her tumour-specific knowledge.

Partnering with a local support group (Prostaid in Leicestershire) helped to generate referrals in the wider community of men with prostate cancer.

What could have been better

Not everyone who was booked in to a session attended, so attendance was sometimes lower than expected. Overbooking sessions would help to address this in any future service.

Some patients thought that the service would have benefited them more if it had been available at an earlier point in their diagnosis and treatment. This appears to have been more indicative of the sheer number of patients needing self-management support than incorrect targeting of the service.

Penny Brohn found that applying for funding from Prostate Cancer UK was complicated. The charity had to apply separately to deliver similar services in different parts of the country. They ended up with multiple contracts, and sometimes more than one contract in a given location.

Most referrals into the service in London were from female health professionals. One service deliverer thought that male clinicians were less enthusiastic about the service, possibly because they viewed 'holistic' treatment as less effective than traditional clinical approaches.

Healthcare professionals didn't have enough time to devote to the services as Penny Brohn had hoped. It can be hard to get them together at the same time to support group sessions with patients.

Outputs

In output term, the service performed well, with all its anticipated events being held:

- London: one Living Well Course was attended by 11 men (target: 9) and no partners (3)
- London: three Health and Wellbeing clinics was attended by 46 men (target: 68), 21 partners (22); 16 were men were Afro-Caribbean
- Leicestershire: one Health and Wellbeing clinic was attended by 6 men (9) and 2 partners (3)

The numbers for the third Health and Wellbeing clinic in London were low, which affected the overall performance at Bart's. This was put down to particularly bad weather on the day, and a low turnout by those who were booked in to attend, rather than a lack of interest.

Management and monitoring

The service delivery team were comfortable with Prostate Cancer UK's monitoring requirements, which approximated their own quite thorough evaluation and monitoring processes. The only challenge was the number of separate contracts being delivered, as mentioned earlier in this case study.

The service used a range of outcome measurement tools, including MYCAW (for the 'clinically significant' measures in the table below) and Penny Brohn's own Health Activation Questionnaire. Overall, outcome performance has been strong, as the table shows. Where there has been underperformance, this appears due to a low questionnaire response rate, which means that percentages are of much smaller participant numbers (Leicestershire in particular, where only two of eight participants provided feedback).

Outcome performance

Outcome	Target	Actual	Variance
Clinically significant improvement in the severity of main prostate cancer related concern	60%	24%	-36
Clinically significant improvement in wellbeing	50%	35%	-15
Increase in awareness of other available support services in local community	50%	74%	+24
Increased awareness of reoccurrence and possible associated symptoms	50%	65%	+15
Increased confidence in managing the impact of treatment and the subsequent long term side effects (i.e. fatigue, ED, continence)	50%	59%	+9
Increased confidence in self-managing the impact of prostate cancer and treatment incorporating the whole person approach	50%	18%	-32
Increased confidence to make changes towards a healthy lifestyle and understanding the benefits of better physical wellbeing	50%	68%	+18
Increased knowledge and understanding of impact of prostate cancer diagnosis and treatment (including being more confident to ask questions)	50%	78%	+28
Increased opportunities for peer support	50%	85%	+35
Increased understanding of using self-help techniques to improve mental and spiritual wellbeing	50%	29%	-21
Increased understanding of ways to improve mental wellbeing including managing stress better	50%	76%	+26

Value for money

Budget suitability

On the whole, the service delivery team thought that the budget was about right. Penny Brohn had experience of delivering these services before so had a good understanding of the delivery costs, more so for the Living Well courses. The Health and Wellbeing clinics were slightly under-costed in terms of set-up and development time put in by the charity's management.

Cost savings

There is no direct evidence of cost savings, but the delivery team are hopeful that the service will have a broadly positive impact through its low level psychological support to men and their partners, which may help to reduce some of the burden on GPs. As one service deliverer put it: “The whole point is to support people to self-manage and, if they do access services, they do so more effectively because they are better informed about their own health.”

Future funding and delivery

Penny Brohn was disappointed that the tumour-specific service would not be continuing with further Prostate Cancer UK support. As one service deliverer put it: “On their and our behalf we’ve developed a capacity, local knowledge, relationships for recruitment, training, and they’ve called all that to a halt. We don’t know what happens next...but there is the most massive need from men for survivorship support.”

The charity will continue to deliver a generic version of the Living Well course nationwide (the Health and Wellbeing clinics will be delivered in one region of the country with the help of Macmillan funding), which some men have previously attended. In this sense, the experience has helped the charity to demonstrate how the services can generate positive outcomes for people with prostate cancer, and it reports some “minor successes” in promoting the service to Clinical Commissioning Groups.

In London, clinicians at Bart’s are keen for the Health and Wellbeing clinics to continue, although there is no funding available. The hospital intends to run four sessions in the future based on the clinic approach, but without the involvement of Penny Brohn.

Annex B: Outcomes measurement

For the analysis of the outcomes of the Commissioned Activity there was a process to group the large amount of data. Initially the 131 projects were grouped into the seven intervention themes, which broadly described the type of project. Each of these themes had a set of Key Outcomes, set out in the table in this annex. This framework, with the key outcomes for each of the Intervention themes was developed after activity had been commissioned. As such each of the projects had a list of outcomes that reflected the specific details for each project. In interpreting the exhaustive list of outcomes, we coded these into the Key Outcome themes from the framework and tidied the data so that beneficiaries within a project weren't double counted for a Key Outcome.

Intervention theme	Key outcomes	Current tools being used	
Self-management	<ol style="list-style-type: none"> 1. Awareness and understanding of risks and sides and symptoms of prostate cancer 2. Awareness and understanding of treatment options 3. Awareness and understanding of side effects of treatment and managing those side effects 4. Awareness of and ability to access support services and information 5. Aware of benefits of healthy eating and exercise 	Before/after questionnaire	
	<ol style="list-style-type: none"> 6. Able to function/go about day to day life 	MYCAW Dartmouth Coop Booklet FACIT FACT-P EQ5-D Holistic Needs Assessments Outcomes star CORE-10	
	<ol style="list-style-type: none"> 7. Reduced stress and anxiety 8. Improved mental and emotional wellbeing 	GAD Perceived stress scale Hospital Anxiety and Depression Scale PHQ Edinburgh-Warwick mental wellbeing scale	
	Targeted communities of interest	<ol style="list-style-type: none"> 1. Health professionals/support group leaders/volunteers have knowledge and confidence to provide/sign post to accessible and culturally appropriate services. 	Before/after questionnaire
		<ol style="list-style-type: none"> 2. Men have increased access to services 	
		<ol style="list-style-type: none"> 3. Men are aware of risks 	
		<ol style="list-style-type: none"> 4. Men are aware of support services/information they can access 	
		<ol style="list-style-type: none"> 5. Men are aware of diagnostic options 	
<ol style="list-style-type: none"> 6. Services developed take account of the views and needs of men and their families 			
Physical activity	<ol style="list-style-type: none"> 1. New skills 	Before/after questionnaire	
	<ol style="list-style-type: none"> 2. Increase access to statutory services 		
	<ol style="list-style-type: none"> 3. Knowledge of benefits of being active/physical activity 		

	<ol style="list-style-type: none"> 4. Improved emotional wellbeing 5. Improved physical wellbeing 6. Fatigue management 7. Increased activity levels 	<p>EQ5D</p> <p>FACIT</p> <p>FACT-P</p> <p>GAD</p> <p>Perceived stress scale</p> <p>Warwick-Edinburgh Mental Wellbeing Scale</p> <p>Scottish Physical Activity Screening Question (Scot-PASQ)</p> <p>CORE-10</p> <p>Holistic Needs Assessments</p>
Care Coordination	<ol style="list-style-type: none"> 1. Knowledge of local services (and how to access them) 2. Effective/sustainable signposting/referral mechanisms 3. Improved local support 4. HPs understand about condition and its impact 	<p>Before/after questionnaire</p> <p>Holistic Needs Assessments</p>
	<ol style="list-style-type: none"> 5. Reduced isolation (from HPs/support services) 	<p>MYCAW</p>
Advanced disease	<ol style="list-style-type: none"> 1. Awareness and understanding of side effects of treatment and managing those side effects 2. Awareness of and ability to access support services and information 	<p>Before/after questionnaire</p>
	<ol style="list-style-type: none"> 3. Able to function/go about day to day life 	<p>Dartmouth Coop Outcomes booklet</p> <p>MYCAW</p> <p>FACT-P</p> <p>Holistic needs assessments</p>
	<ol style="list-style-type: none"> 4. Reduced stress and anxiety 5. Improved mental and emotional wellbeing 	<p>Hospital anxiety scale</p> <p>Perceived stress scale</p>
Psychosexual support	<ol style="list-style-type: none"> 1. Ability to share experiences/concerns 2. Acceptance of condition 	<p>Before/after questionnaire</p>
	<ol style="list-style-type: none"> 3. Awareness and understanding of side effects and their management (ED) 4. Improved emotional and physical wellbeing 5. Improved relationships 	<p>CORE 10</p> <p>Holistic needs assessments</p>
		<p>Sexual health inventory for men (SHIM)</p>

	6. Reduced stress and anxiety and depression	Generalised Anxiety Disorder Assessment Hospital Anxiety and Depression scale PHQ-9
Social Prescribing	1. Awareness and ability to access support services and information 2. Opportunities for peer support/social interaction 3. Opportunity to learn new skills 4. Improved emotional and physical wellbeing	Dartmouth Coop Outcomes booklet Before/after questionnaire EQ5D FACT-P
	5. Reduced social isolation	GAD-7 Perceived Stress Scale PHQ-9