



Evaluation of the Health and Social Care Professionals Programme – Annual report 2015

Prostate Cancer UK

July 2015

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Executive summary

Summary of the research

This is the second annual report for the Evaluation of the Health and Social Care Professionals (HSCP) programme. ICF Consulting has been commissioned to provide Prostate Cancer UK with monitoring and evaluation services to support this programme. The aims are to:

- Gather evidence of the outcomes and impacts of the programme as a whole, and its constituent projects;
- Provide objective feedback through ongoing process evaluation in order to improve the management and implementation of the programme; and,
- Work with each project to support their own monitoring and evaluation and share learning across the projects.

Prostate Cancer UK established a set of specific requirements for the work which were for ICF to:

- Work with each of the projects to agree tailored monitoring and evaluation plans;
- Provide ongoing support to projects on monitoring and evaluation;
- Gather and analyse monitoring information from the projects which are submitted on a quarterly basis;
- Provide in-depth evaluation reports for the programme; and
- Support programme management with learning and dissemination.

This report is the third substantial evaluative output from the study (in addition to twenty shorter monitoring reports). It brings together research findings from several sources, including the monitoring and evaluation plans that projects have been supported to develop; an ongoing programme of contact with projects as part of the monitoring and evaluation support; specific catch-up calls with each projects focussed on their evaluation plans; case study visits to three projects; and projects' annual monitoring returns to the programme which provide an update on progress, and views on the processes followed.

The report summarises the impact of the programme to date, the latest input and output data in aggregate; three project case studies; and, a set of lessons learned and recommendations for this programme, and Prostate Cancer UK.

Main findings

Inputs and outputs

At present, project reports suggest a total of 21,378 people have been supported across the lifetime of the HSCP programme. There are now 31 projects which are in full delivery and supporting men. The future potential size of the programme is indicated by the fact that the final total number of projects will be 45. Nearly all (96%) of beneficiaries are male, nearly seven-in-ten (69%) are between 60 and 79 and just under three-fifths (58%) are white, although data are unavailable for one-quarter of beneficiaries. The programme has grown substantially over the last year. In June 2014, the programme had supported 3,192 people.

These men have been supported mostly in one-to-one settings (63% of the support delivered) or through remote support/ monitoring (19%). The varied nature of the programme is illustrated by the latest data on the form of support. The two largest categories – education and psychological support – which make up around two-fifths of the support delivered, are also the two most broadly defined.

Prostate Cancer UK has now committed over £3.5 million of funding, provided by the Movember Foundation and Royal Mail, towards the projects in five separate phases of funding; the average project size for those that are 'live' is around £85,000. Estimated total additional contributions amount to £219,372 or 8% of the total figure committed by Prostate Cancer UK.

Outcomes

Each project has agreed a set of outcomes, tailored to the aims of their project. These can be considered in aggregate against the Movember outcome framework to provide an estimate of the impact of the programme to date:

I am satisfied with the information, care and treatment I received.

Most projects are collecting data on men's experience of the funded service(s). The annual returns suggest that 4,817 men have reported satisfaction with the support or care they received from funded projects. These men come from fifteen projects. There are key themes within the programme of projects which are improving the coordination of advice and care, providing information about treatment decisions, and improving access for men to treatments of their choice. For example, the Christie's phase 2 project has collected survey data which suggest that the radiographer-led follow-up clinic being piloted has provided the 650 men who have used the service, with sufficient time to discuss treatment and side effects during the consultation.

Extrapolating these data on patient satisfaction to the other 'live' projects across the programme which have not yet submitted data in this outcome area suggests that around 10,000 beneficiaries are satisfied with the care received.

I am physically well.

Most of the live or completed projects are collecting data which relate to men's physical condition, including their symptom control, management of side effects of their treatment, their self-reported quality of life or level of physical activity. Six of these projects so far have provided robust evidence of impact in this area. These include, Barts Health and St Joseph's which has collected evidence across a range of physical indicators to suggest that their pilot physiotherapy intervention has improved outcomes related to fatigue, quality of life and in relation to lower urinary tract symptoms following radiotherapy.

The evidence base in this area is likely to grow. A further six projects are using validated measures to measure the impact of their projects on a set of health outcomes reported by men. In order to gather follow-up responses, and to establish the impact of interventions over a longer period of time, these projects will provide these data towards the end of their funding period. NHS Lothian, for example, is assessing the impact of a pilot pre-prostatectomy physiotherapy intervention on 60 men over the course of one year (in order to understand the long-term efficacy of the intervention).

I am mentally well.

Several projects are collecting data on the extent to which the funded service(s) are supporting men to manage their condition better than before, or whether they feel more empowered to manage their condition and care. An assessment of the data presented by projects suggests that 2,514 men from six projects have been supported to manage their condition better. This evidence comes from a range of projects including a large-scale pathway re-design project, as well as smaller scale projects delivering telephone support. Extrapolating these data to the other 'live' projects across the programme which have not yet submitted data in this outcome area (but are expected to) suggests that around 5,000 men have currently been supported to manage their condition better.

My family and carers are physically and mentally well.

While not its primary focus, the programme is also supporting families and carers of men. This is a result of the flexibility of the programme in allowing project teams to respond to local need. As a result, around 4% of those to benefit from the programme have been females.

In addition to those outcomes which affect men and their families directly, the HSCP programme has also sought to generate beneficial outcomes at the service level. These outcomes can be grouped as follows:

- **Generating savings or helping services to operate with greater efficiency.** Responding to local need, several projects aim to introduce new and more efficient ways to manage men's care. Several projects have provided evidence of their impact in this area. This includes Leeds Teaching Hospitals, which has altered the long-term follow-up care of 700 men, transferring responsibility for this from Consultant and CNS-led delivery to a new remote monitoring service.

- **Increased service accessibility.** Two projects have so far provided quantitative evidence of the impact of their service on enabling men to access specialist services more rapidly. This includes NHS Fife's phase 2 project which reported that the introduction of nurse-led support at biopsy and follow-up has reduced average waiting times between biopsy and histology by 41% (from 22 days down to 13 days) and between biopsy and consultant-led follow-up appointment by 13% (from 47 days to 41 days). There is a wider body of qualitative evidence from across the programme which suggests that projects are doing much to improve access to CNSs or other named healthcare professionals, who are then able to provide holistic support or answer questions men have much quicker than if they had to wait for a consultant appointment.
- **Improved understanding of 'what works' in service delivery.** All projects have developed a better understanding of what works in improving services and outcomes for men in this clinical area. The learning has been particularly valuable in the context of projects which have not achieved what they originally hoped to. For example, Brighton and Sussex University Hospitals, which originally aimed to implement a remote monitoring service, reported that their project has gathered vital information for local services about unmet need and patient expectations about the service they intended to pilot.
- **Improving the skills and knowledge of other healthcare professionals.** To date, thirteen projects have established outcome indicators which relate to activities post-holders are undertaking to educate other healthcare professionals, most prominently in community or primary care settings. Data has been reported by four projects which suggest that the programme has improved the skills or knowledge of 218 healthcare professionals so far.
- **Generating sustainable change.** As the programme matures, and projects' funding approaches completion, the extent to which the services piloted are sustained (and the nature of this sustainability) becomes a more important question. At present, eight projects have robust plans in place to sustain the funded posts or activities to some degree. There are a number of emerging models for sustainability. Projects have successfully used the funding to:
 - Develop and then embed a new care pathway within existing services;
 - Illustrate the demand for a new role / service with the roles then supported by mainstream resources;
 - Develop the skills and experience of existing staff to fill more senior roles.

Lessons learned

The scale and impact of the HSCP programme

The evidence presented in this annual report describes a programme which has grown rapidly over the last year. With a further fourteen projects scheduled to start over the next six months, the programme is forecast to continue growing.

The evidence of impact across the programme is strongest in relation to patients' experience of services and support provided to self-manage their condition. As the programme progresses, a wider evidence base on the impact of funding on men's self-reported health outcomes is expected (although there is already evidence here, especially in relation to supporting men to become more active, improve their quality of life, and has also impacted on men's emotional and social wellbeing).

The programme has also produced a rich and expanding qualitative evidence base on the process of implementing these service development projects. The insights into what works in managing projects and programmes of this sort, and how to transform urology services (particularly in follow-up care) are likely to be of interest beyond the programme and Prostate Cancer UK.

The early evidence from the projects which have finished (or are approaching their completion) is that the programme has supported a highly sustainable set of interventions. Post-holders from sustained projects have identified key factors driving this sustainability. These include: establishing a robust initial case for action, strengthening this with high quality scoping research and building on this by collecting a robust evidence base of the need for the service and its impact through delivering the

project. Other projects have shown the value of embedding activities into existing services so that their continued delivery is not contingent on particular individuals.

Programme and project management

Projects continue to face challenges across the project management cycle ranging from recruitment of staff through to ensuring the sustainability of interventions. The consistency with which these risks have been reported across the lifetime of the programme also illustrates the intractability of some of these challenges; there is only likely to be a finite amount that programme and project managers can do to mitigate them.

Programme management is addressing these challenges proactively. Quarterly catch-up calls and more regular visits to projects are key elements of this enhanced support. There is also some evidence that the newer projects are benefiting from the experience of older projects including learning about evaluation, recruitment (to some extent), project scoping and delivery.

Projects also regularly report the several areas of 'added value' that they gain from being part of the programme and the links with Prostate Cancer UK. This includes the patient advice literature developed by Prostate Cancer UK, educational opportunities and bursaries, and the programme networking events.

As the programme progresses, there are opportunities for more 'value-added support' to be delivered by Prostate Cancer UK. There is scope (and demand) for Prostate Cancer UK to offer more support in actively facilitating networks of projects, sharing evaluation findings with projects, assessing whether there is scope for research outputs to be produced across several projects, and providing more formal business planning support, perhaps by sharing best practice examples.

Learning from the programme

As the programme matures there is a growing body of learning for projects, evaluators, the programme team and the wider charity. There is learning at three levels:

Designing, managing and evaluating a programme

There is much to learn from the delivery of the HSCP programme about the design, management and evaluation of future programmes. There are several criteria which should be considered when scoping out future programmes. These relate to the:

- Focus of programmes – *should they be tightly themed around particular service challenges, or open calls allowing projects to develop interventions in response to local need?*
- Size of projects and programmes – *should they consist of fewer but larger projects or many smaller projects?*
- Funding of projects – *how can funders use the commissioning phase to attract the highest quality bids?*
- Contract duration – *what is the optimal length for projects to be funded for?*
- Programme monitoring – *how can programmes establish monitoring systems which add value to projects as well as ensuring accountability?*
- Programme evaluation – *how can programmes and funders best support project teams to self-evaluate given the challenges faced with capacity and capability to do so?*

Project management

As projects have progressed, a number of factors informing high quality project management have been identified. These include: setting up formal steering groups to keep key project stakeholders up-to-date with progress; understanding how different stakeholders measure success; developing back-up plans for the (inevitable) personnel challenges; and considering sustainability from an early point in the project. Where possible, projects have also emphasised the value of the post-holder being supernumerary for the induction and scoping phase as this allows time to familiarise themselves with the service and goals of the project.

What works in delivering high quality follow-up care for men with prostate cancer

In the process of leading change activities in their local areas, projects have identified a range of challenges facing follow-up services for men with prostate cancer. These challenges may inform future strategy for Prostate Cancer UK. Key themes include: the continued need to improve the integration of services (such as the quality of information which follows men from secondary to primary care); the continued need to raise awareness of prostate cancer among at risk groups; and the potential for an expanded role for the allied health professions in delivering follow-up care.

Delivery of the programme has also provided further evidence of a shortage of senior nursing skills in this clinical area; several projects have illustrated how they have partially addressed this skills gap within their service by developing post-holders' skills.

Recommendations

Based on the evidence gathered to date, a set of recommendations for the programme management team, and Prostate Cancer UK more generally, have been developed.

Recommendations for the programme team

The programme team management team should:

- Continue to catch up with projects on a quarterly basis. These calls should ask projects about progress against the indicators agreed in the monitoring and evaluation plans and discuss the reasons for variation;
- Using these calls, focus more resources on higher value support for projects, including facilitating networks, sharing best practices / approaches other projects have developed, signposting to other opportunities, other projects approaches to sustainability;
- Establish a quarterly newsletter which would include headline findings drawn from the quarterly reports, patient and project case studies, information about evaluation and research tools being used;
- Organise more networking opportunities. This may include a whole programme networking day (likely taking place in summer 2016, and focused on programme impact and sustainability) or a smaller day targeted at newer projects;
- Establish a working group / virtual group to examine possible collaborative research studies across projects. A possible subject for an initial collaboration would be to analyse the common service delivery challenges projects are facing.
- Begin the process of gathering projects' products (for example, documents associated with pathway re-design, or national service audits), where there is a sense that wider value may follow. These products should then be made available across the programme and within Prostate Cancer UK.

The monitoring and evaluation team should continue to undertake initial visits with all new projects, using learning from previous projects to establish evaluation plans which are:

- Defined by the projects themselves (guided by ICF researchers);
- Focused on collecting data on those indicators which are of most importance to the projects and their future sustainability.

Future rounds of qualitative interviewing with projects should focus on the questions most appropriate for a programme at this stage of its development. This includes the impact of projects, key factors which contribute to sustainability, and any learning projects have accrued about the challenges facing their local services.

Recommendations for future programmes of this type

In considering its future strategy, and any future programmes Prostate Cancer UK should build on the learning from the HSCP programme. Future programmes of this type should:

- Be more tightly focused thematically, and linked to wider activity within the charity (for example, influencing work). Programmes should be funded to help 'make a point';

- Offer longer funding posts – of say three to four years – including a discrete scoping period of up to six months at the beginning of projects in which project teams are recruited and other scoping studies are undertaken;
- Support fewer, larger projects which will enable programme management to focus their time and support more closely;
- Focus monitoring and evaluation on a small number of measures that really matter – agreeing these with funders at the outset;
- Consider mechanisms for re-allocating resources between projects, such that those with the greatest effect might be extended (in time / scope);
- Provide support for non-clinical staff, or fund posts that do not have clinical caseloads, to provide more project management and administrative support;
- Retain the flexibility to allow projects to define their goals in response to local need.