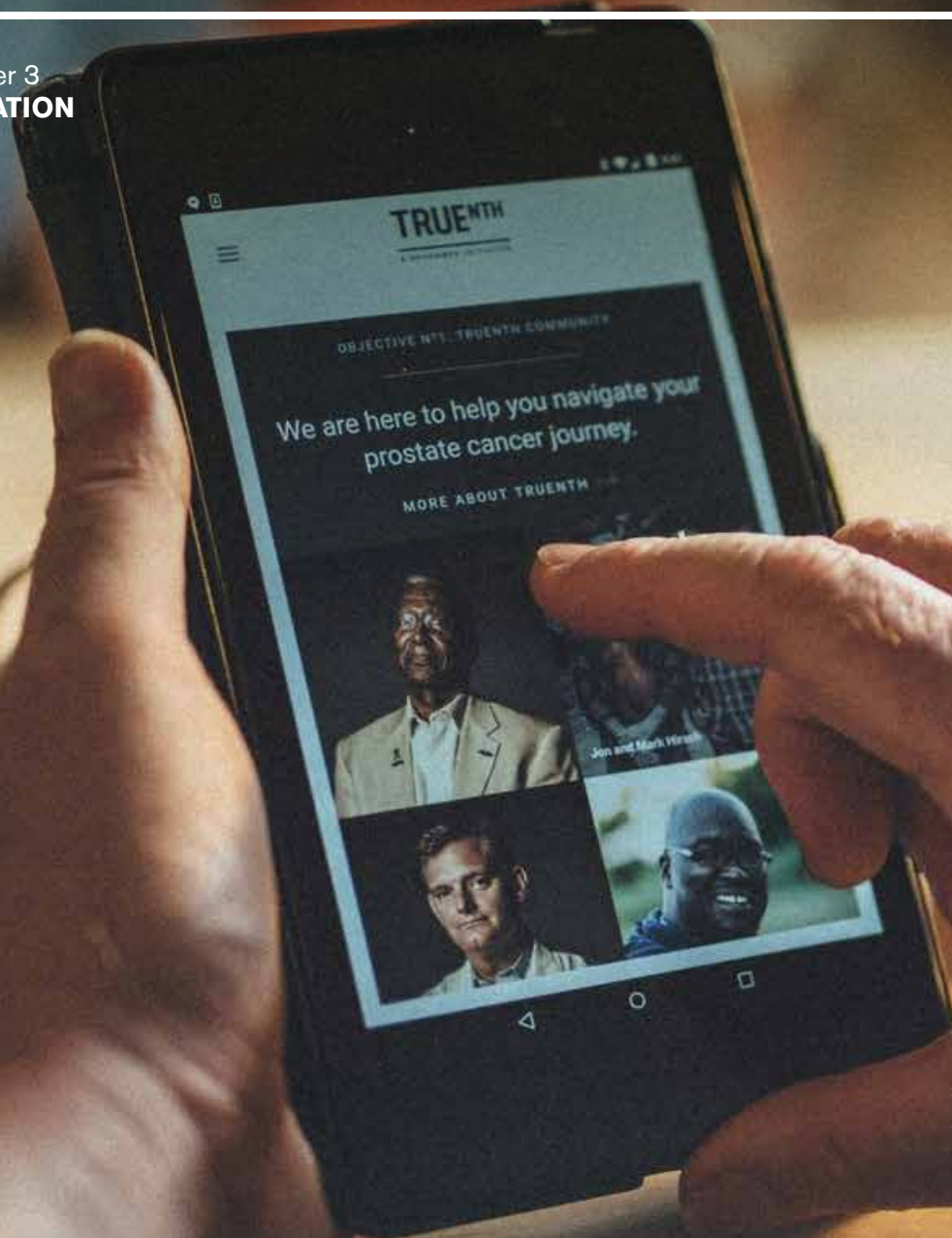


Appendix C:

Evaluation of the TrueNTH UK Supported Self-Management and Follow-Up Care Programme

Technical Report Number 3
QUALITATIVE EVALUATION
October 2017



UNIVERSITY OF
Southampton

The work reported here is part of the TrueNTH global initiative, led by the Movember Foundation, to tackle critical areas of prostate cancer care. TrueNTH is an international network of representatives which includes clinicians, academics, patients and organisations from across the UK, Canada, Australia and other countries. Through this initiative we are working together to identify and demonstrate the best and most cost-effective models for improving prostate cancer survivorship care and support. In the UK, the TrueNTH partnership of healthcare professionals, academics and volunteers is managed by Prostate Cancer UK

The work reported here is part of a programme of work to develop, implement and evaluate a supported self-management and follow up care programme for men with prostate cancer, which was led by a team from the University of Southampton.

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1. INTRODUCTION

The qualitative research reported here is part of a mixed methods evaluation of the TrueNTH Supported Self-Management and Follow up care programme (henceforth referred to as the programme) which involved four NHS sites in England.

The programme consists of a nurse-led supported self-management and remote surveillance follow up care pathway implemented within secondary care. The aim of the programme is to better address men's unmet needs, as well providing a more sustainable model of care within the context of increasing demand. The programme is described in detail elsewhere (1).

Risk stratified models of follow up care have been recommended for cancer survivors for implementation in England by 2020 (2). However, whilst development work has been undertaken with breast, colorectal and testicular cancer (3, 4), this study is the first to evaluate the introduction of such a model for prostate cancer patients.

The implementation and evaluation of the programme was funded by Movember, in conjunction with Prostate Cancer UK. The objectives of the evaluation were to assess:

- i) the effectiveness of the programme across key outcomes;
- ii) the impact of the programme on costs;
- iii) the process of implementing the programme, in order to identify any facilitating and inhibiting factors.

This technical appendix presents findings that relate to the third objective. Technical reports on the evaluations of effectiveness and cost effectiveness, and a summary report are also available.

The qualitative evaluation aimed to document health care professionals' and patients' experiences of follow up care and of the programme, and to elucidate any processes which might have promoted or inhibited the implementation of the programme.

This report first details methods used in the qualitative work. It then presents the main findings regarding the implementation of the programme: the acceptability and perceived value for both staff and patients; implementation of each of the main processes/component parts of the programme; and finally, sustainability and spread of the programme at the sites taking part.

2. METHODS

The evaluation methods are described in full in the open access protocol paper (1) available at <http://rdcu.be/v1d9> , so only a brief description is given here. The evaluation of the programme took place in four prostate cancer treatment centres in NHS Trusts in England (in this report termed 'the sites').

The qualitative study was embedded within an evaluation of the effectiveness of the programme, which involved questionnaire data collection with a group of men in the programme and a pre-service change comparator group of men. Men involved in the qualitative study were a subset of the questionnaire cohort.

Successful implementation of the programme relied on it being adopted and implemented at organisational, staff and patient levels. Interviews were therefore conducted with staff involved in different ways in the programme's implementation (e.g. lead implementers; involved clinicians; managerial staff) and with men who were enrolled on the programme.

In order to be able to view the programme within a context of change, a small number of interviews with men who were part of the comparator group were also conducted to examine understandings of and interaction with clinic-based follow up care. These men had been migrated to the programme at the time of interview and were able to make a comparison between the two modes of follow up care.

Normalisation Process Theory (NPT) (5) was used to inform the interview topic guide, sensitising it to factors important to the embedding of the intervention at the sites taking part.

Approaches for interview were made to each of the lead teams (lead consultant, lead clinical nurse specialist (CNS) and support worker) at the sites, who were then asked to identify wider team members who had been involved with the programme; up to 10 staff members were approached at each site.

Men were purposively selected from their baseline questionnaire responses, to ensure men with a range of different socio-demographic and medical variables were interviewed. Men were selected based on age; ethnic group; access to the internet at home (programme group men only); type of treatment and time since diagnosis. Men were randomly selected per site for each of the criteria separately, from those men who had indicated their willingness to be approached for interview.

The study's Project Manager was also interviewed.

The aim of a qualitative study is to provide an in-depth understanding and small sample sizes are used for this. We attempted to talk to a range of staff and to select men who would be representative of the range of men involved in the programme.

Semi-structured interviews were mainly conducted by telephone, with one staff interview and two patient interviews being conducted face-to-face, either for convenience or preference. Interviews with staff were conducted by RL and lasted between 22 and 90 minutes, with a mean length of 47 minutes; generally, interviews with the lead team were of longer duration (51-93 minutes). Interviews with men were conducted by RL, JN and JF and lasted between 24 and 85 minutes (mean = 52 minutes). The interviews with staff took place between April and November 2016, being 12-18 months after start of the programme. The interviews with men were conducted between October

and December 2016, an average of 7 months after completion of their study questionnaires (range = 1 to 18 months).

Interviews were transcribed in full, transcriptions verified, and uploaded into NVivo citation (6) for analysis. Development of the initial coding frame was a largely deductive process, taking as an initial structure the aims of the evaluation, the programme's theoretical underpinning and NPT, but also allowing for inductive codes to emerge from the data. An initial coding frame was developed and agreed by JF, RL and JN, working with a small number of transcripts. This was then adapted by JF and AR following application to a larger number of cases. Detailed coding and analysis of the staff interviews from one site was undertaken by RL. The remaining coding was undertaken by JF. Analysis used the method of constant comparison and with a search for deviant cases (7). Data, coding and interpretation were reviewed by AR, with queries being discussed and resolved.

In order to maximise anonymity, quotations from staff are presented with job role only. Quotations from men have been given a patient number.

The study received ethical approval from the National Research Ethics Service, East of England – Cambridge South (reference number 11/EE/1021). In addition, research governance approval was received from the individual NHS Trusts involved with the study, and the project was adopted by the National Institute of Health Research Clinical Research Network (ID 17238).

3. RESULTS

This section first characterises the interview participants. It then considers the acceptability and perceived value of the programme to staff and patients. Next, it presents data on implementation of the programme, looking at each key aspect in turn. Finally, it considers the sustainability and spread of the programme at the sites.

3.1 Participants

A total of 32 interviews were conducted with staff and 39 with patients.

Forty five Trust staff were invited for interview and 13 did not consent. Interviews were conducted with a range of staff members (Table 1), including all four of the lead CNSs and support workers, three of the lead consultants, at least one other CNS at each of the sites, a total of eight other consultants, five people in clinical management roles and one in a non-clinical role.

Table 1: Details of interviews conducted with staff.

	Site 1	Site 2	Site 3	Site 4	Totals
Lead clinician (consultant)	1	1	1	0	3
Lead CNS	1	1	1	1	4
Support worker	1	1	1	1	4
Other CNS	2	1	1	1	5
Other consultants	2	3	1	2	8
Clinical management	1	0	4	0	5
Non clinical role	1	0	0	0	1
Other		1	1	0	2
Totals	9	8	10	5	32

Interviews were conducted with 31 men from the programme group and 8 men from the comparator group. 67 men were invited for interview and 49 consented (73% of those invited); 9 consented but were not interviewed, either because they were not available at the time the interviews were being conducted or because the sample number for their hospital had been achieved (these men were thanked in writing for their interest).

Ten men were interviewed from three sites and nine from the fourth (see Table 2). Socio-demographic and medical characteristics of the men interviewed, taken from their questionnaire responses, are given in Table 2. The mean age of men interviewed was 70 years (range 51-82); just over a third (n = 12) had A level or undergraduate education; more than half (n = 22) had had radiotherapy and a third (n = 12) had had a radical prostatectomy; two of the men interviewed were from non-white backgrounds; and almost two thirds (n = 23) were within one year since their treatment. Using the Index of Multiple Deprivation (IMD) (8), 3 of the participants lived in the 20% most deprived areas of England and 4 participants in the 20% least deprived areas. Thirty four of the men reported having access to the internet when at home.

Table 2: Socio-demographic and medical characteristics of men interviewed

Patient characteristic	Number of men		Number of men
Centre		Employment Status	
1	10	Retired	31
2	10	Employed full time	2
3	9	Employed part time	4
4	10	Self employed	1
		Disabled or long term sick	1
Evaluation group		Marital status	
Programme group	31	Married/civil partnership	32
Comparator group	8	Widowed	4
		Divorced/separated	1
		Single	2
Type of treatment		Access to the internet at home	
Brachytherapy/hormones	2	Yes	34
External beam radiotherapy	4	No	5
External beam radiotherapy with hormones	18		
Hormone therapy	3		
Radical prostatectomy	12		
Ethnicity		Index of Multiple Deprivation decile (8)	
White	37	1	1
Other	2	2	1
		3	2
		4	4
		5	6
		6	2
		7	6
		8	9
		9	4
		10	3
		Missing	1
Qualifications		Age of participant (in years)	
No qualifications	7	Mean	70
GCSE/O level	5	Range	51 to 82
Vocational	10		
A level	6		
Undergraduate	6		
Other	5		
Time since diagnosis (years)		Time since most recent treatment	
Mean	2	0-1 Years	23
Range	0-11	>1 to 2 years	9
		>2 to 3 years	7

3.2 Acceptability and perceived value of the programme

3.2.1 Staff views

The teams from the four sites responded positively to the introduction of the programme and valued it. At the time when the interviews were conducted, it had become normal, routine practice for all of the site teams.

The perceived value of the programme was seen by most as addressing the contemporary problem of overloaded clinics, and the impact this had on timeliness of patient reviews:

If you look at your system and you think there is no need for improvement then you don't need TrueNTH. But if you look at your system and you see over crowded clinics, if you see patient waiting lists and if you see that, you know, in the kind of current financial climate, more doctors, more clinics, more nurses aren't going to be available then, you know, you have to think of a different way of approaching it. And this is a different way of approaching it within a safe framework. (CNS)

But, you know, in an overcrowded system...where the actual date of a clinic could be moved, I think this is probably safer in terms of, you know, keeping things to a regular time frame. And keeping patients involved rather than bringing them kind of up to clinics that are delayed or cancelled, so I think it keeps things much more standard. (Consultant)

The value of the programme in survivorship care was recognised by some:

I see it as getting the patient ready to live their life after their diagnosis of cancer. And I think although we thought we were doing that before, I think we probably, we certainly weren't encompassing everything about getting ready to live their normal life. (CNS)

The programme was considered as potentially safer than an overloaded clinic system, largely because of the presence of a dedicated support worker who would ensure that men completed their follow up review:

They've got somebody specific that will kind of--- making sure that they have--- are having everything done, which other patients don't. (CNS)

In practice, while the number of new patients seen was keeping consultant-led clinics busy, there was a perceived reduction in workload in both CNS-led clinics and consultant clinics. This meant patients could be seen more promptly and could be given more time:

I mean the impact of the programme on the clinic has been number 1) the clinics are gradually having a little bit more capacity to accommodate other more urgent cases. And, so obviously, it's still some way to go but that will keep getting better with time...And then secondly, I'm not sure what other impact will it have on the clinic except to have extra capacity in the clinic. But obviously then when you see a little bit less number of patients, you have more quality time to talk to them and then you feel a little bit more satisfied with the outcome (Lead consultant)

And what we have noticed, and the oncologist has commented on, is that he's seeing more complex patients rather than the kind of straightforward patients, you know, or mix of more straight forward patients versus complex patients, that he might have seen in the past. And hopefully that's an effect of us taking stable patients out of the clinic. You know, and we know that the patient, as I say, the treatment options are broadening for the patients with advanced disease so they're staying with the new system longer so hopefully, you know, it gives the doctors more time to spend with the patients that need it. (Lead CNS)

3.2.2 Men's views

You know, we're intelligent, we understand our problems. If people explain what they were looking for you can self-monitor without a problem. And that's what TrueNTH does. (Patient 5)

On the whole, the men who were interviewed were positive about the programme. The value of the programme for most was in the reassurance that came from knowing they were being monitored and could get in touch easily

I'm quite happy for it (PSA) to be monitored from time to time and if there's any need for me to contact anyone then I can do. But I have no need at the moment and as such that's fine. I know it's there. It's a comfort blanket if you like. (Patient 25)

The alternative would have been to have had treatment, the treatment finishes and then you feel abandoned. Well that certainly wasn't the case. I had the treatment, had the cure, but "We're here if you need us". That was jolly good. (Patient 6)

Patients saw time benefit in not having to attend hospital for a short consultation to be told everything's fine. They considered this to be a legitimate move for the hospital, to free up appointments for people who were less well and needed to be seen:

Well, yes. Because frankly I would go to [name of hospital], park the car, go in there, sit there for three quarters of an hour or whatever. The guy would say: we--- you've had your blood test, the results are negligible on PSA. How are you? Are you fine? Yeah. Thank you. Right. Bye. And then--- so then that would be it. So I couldn't see any disadvantage in the method as--- as now is where I do a blood test anyway and providing that's still, there is no need for me to see a doctor and take someone else's appointment who might be more in a serious condition or whatever. So it seems from everybody's point of view to be a win-win situation. (Patient 25)

A number of men who were very well and were getting on with life saw potential value in the programme but did not consider it of benefit for themselves within their current situation:

It's a good system and I'm sure it will benefit a lot of people, but it's not of any great benefit to me. (Patient 12)

There were a small number of men who were less positive about the programme, in that they felt left on their own or they preferred face to face contact:

I mean the strange thing I couldn't get my head around was that there didn't seem to be any follow ups or anything. You know, they took you in, they done the operation, they sent you home and you had your radiotherapy and that was it. Good bye and best of luck sort of thing. So I thought that was a bit of a weakness. (Patient 14)

I used to like go to the hospital because you speak to the doctor. You feel more sure. No, going to the hospital sometime you feel a bit--- I don't know. You know, sometimes you feel that you can always talk to the doctor and--- I don't know. He's always--- say if there's something on the back of your mind, you can always ask. And when you go to ring them sometime you think: oh, you know, I don't want to disturb them (Patient 13)

3.3. Implementing the programme

3.3.1 Introducing the programme and driving it forward

The work of introducing the programme to teams and the Trusts and of driving it forward was undertaken by the lead clinicians and lead CNSs, with contributions from the support workers once in post. Once set up, the day-to-day running was left to the lead CNS, who also took line management responsibility for the support worker. The lead team needed to introduce the programme to a variety of staff members, including their immediate urology/oncology colleagues, wider management, and to the IT and pathology departments from whom input was required. The team's role was to ensure that the right people understood the project and were ready to work on it.

The programme was introduced to the uro-oncology teams at their regular meetings, to inform, discuss and answer queries. Presentation and discussion of the programme continued throughout the implementation period.

The sites involved in the evaluation were at a point of readiness for the programme; in particular, they had some familiarity with non-face-to-face follow up care (e.g. telephone clinics or other remote systems) and/or CNS-led clinics, and had been considering the need to find new ways to manage the increasing number of men in follow up care:

We had explored different systems for follow up of our prostate cancer patients so there was already an impetus in that direction. So no one expressed any concerns, they all seemed to, you know, see the benefits of it (Lead CNS)

However, elements of the programme were novel to all sites, and there were concerns among clinicians that had to be addressed: about earlier discharge of patients from their care; about the workshop and its content; and about receptivity of patients to a remote system:

We had to do multiple sessions to inform people about what the programme is about. What are the inclusion criteria? And how will these patients be followed up? To try and reassure them that this will be safe and those patients who, for example, a particular consultant has been following up, that even if they let go of that patient, the patient will be safely followed up. So all those issues I had to pick up and answer for the team. So, yes, there was a bit of training involved for the department and for the team. (Lead consultant)

Some sites also gave presentations about the programme more widely, though little work was done to introduce the programme to the wider health care system, (for example, GPs) and this was identified as a necessary step which could have been addressed earlier on in the implementation.

As the implementation of the follow up care programme came with funding, the process of management approval was relatively smooth. Nonetheless, managers could foresee the value of the programme in addressing problems of clinic capacity. Processes of seeking continuation of funding at the end of the funded period are discussed in the section, 'sustainability and spread'.

In setting up the programme at the sites, there was quite a lot of work to be done by the site's IT departments, for instance in setting up the interface for the systems internally, in pulling pathology and demographic updates through to the system, and in linking to the external host. There were also information governance issues to be addressed. Sites found that this work could take longer

than initially perceived. Advice was to involve the relevant IT and pathology teams very early on in project planning:

I think before anything is discussed, I think you need to get IT on board; because they felt they'd been left out and not brought in 'til later on. So I think if you're looking at a project like this, I think IT have to be involved from the very start. At the beginning with all the talks going on. Because I think if they'd been brought in earlier, they could have suggested things and told us that: "hey, this not going to happen for another couple of months" rather than the team get frustrated because nothing was happening. So I think out of all of this, I think IT has to be brought in from the very start into talks. (Manager)

The programme was overseen throughout the evaluation phase by an external project manager, who supported the sites in its initiation and implementation. Within the sites, the lead CNS was funded to undertake the day to day management of the project, including project management, a role that was nevertheless sometimes difficult to fit within a busy workload.

3.3.2. Introducing the support worker role to the uro-oncology team

The support worker is the mainstay of programme delivery. The support worker roles include: promoting referral of patients to the pathway; managing the IT system; organising and co-running workshops; being first port of call for patient queries; and involvement in Prostate Specific Antigen (PSA) tracking virtual clinics.

The Lead CNSs in particular felt the value of the support worker role in relieving their workload:

At the end of the day these are well patients so having somebody there who's just being an extra pair of eyes on things has released the Band 7's to go and do more things and more appropriate use of the time (Lead CNS)

I know I say she's good but actually it's the support that you get from that person. It's worth its weight in gold. I'd far rather have her than I would another nurse specialist. Because with another nurse specialist you end up developing something else, without actually sorting out what you've already got. (Lead CNS)

In addition to this, the support worker was able to contribute to the work of the wider team:

So although the programme in itself, and what it's done for patients, has been fantastic, the additional thing in terms of having another member of the workforce that understands a bit more about prostate cancer, and a bit more about the dynamics of the team and they can be supportive and helpful, and everything else, that added value has been great. (Consultant)

There were some early concerns among the teams about whether a Band 4 worker would be able to undertake the job roles successfully, and getting the right person was seen as key:

And I think that...was a big concern...putting her in front of patients. And I think, you know, I've seen in her action now a couple of times in those settings and she's very, very good (Lead consultant)

Important attributes included interpersonal skills, IT skills, organisational skills, compassion, but not necessarily knowledge of prostate cancer, which could be learnt. As a new role, the team needed to work out how the role would be fitted into the team and to decide which roles could be delegated to the post. Over time, trust and confidence in the individual support workers grew and they were given more responsibility.

and I think obviously to begin with, it was kind of like just working out what the role entailed, what responsibilities a support worker could take on. But over the time...over the two years, that's obviously been ironed out and it works very well now (Lead CNS)

I think we need, as nurse specialists, to stop being so precious about what we do because there's a lot of things that we do that we don't need to, that we can hand over. And that's what I think we find difficult. And there's a lot that if we let go, that [the support worker] could do just as good a job actually. (Lead CNS)

This delegation of responsibility varied between sites, however. There was debate, in particular, regarding the support worker role in checking PSA results as part of the virtual clinics:

I do have mixed feelings on whether they should or shouldn't check blood results. But again, as I said earlier, I think it's due to the training and the individual person that you have, and their competence, and what their training's like, and the team that they're in. I think if you're in a supportive team and they're not worried about asking then that's fine but if you had a slightly inflexible team, if that's the right word, that might be a bit tricky (Lead CNS)

Much of the support worker training was 'on the job' learning facilitated by the CNS. This could be challenging to schedule but obviously crucial to success:

My advice would be to make sure that you train up your (support worker)... invest that time at the beginning, which can be stressful and can be time consuming, but it is worth investing that time at the beginning of the project to give your Band 4 the tools that they need to be able to run the programme, almost solo. I'm not going to say solo, because it isn't. But they can do so much to take that work for those well patients away from you (Lead CNS)

In addition to training, the role required easy accessibility to the CNSs for advice and support for any queries; the sites found that this was facilitated by physical proximity.

3.3.3 Screening and referral

The main programme role for the majority of clinicians in the uro-oncology team was screening patients for eligibility and referral to the programme. This required behaviour change (being aware of the eligibility process and remembering to assess a patient's suitability when seeing them in a clinic) and a change in thinking (to relinquish care of their patient to a different system at an earlier point in the patient's cancer follow up). The latter change, in itself, required trust in the system. At the time of interview, most consultants were routinely screening and referring their patients to the programme, although there remained a small number of consultants who were slow to refer:

Some colleagues are more reticent to dispose of their patients to that sort of follow up than others. And I am certainly aware of at least one colleague who's a little bit protective and would probably see patients in clinic that others of us wouldn't do. So there's a little bit there that's difficult (Lead consultant)

The lead team at each Trust put a great deal of work into ensuring that these clinicians knew what was required of them in terms of screening and referral and also to support them to enact it within a busy clinic. In particular, the support workers aided clinicians through the advanced screening of clinic lists to identify potentially suitable patients, made themselves very visible to the clinicians, sometimes locating themselves in the clinic area, and continually checked and feedback that referrals were appropriate.

Her involvement made the main (pause)...it was...you know, the milestone of the whole programme because she was always present (INT: yes) for each of my clinics. And she studied the clinic and she looked which patient could be a potential candidate to be involved in the programme. And I think only because of that, and her physical presence, I think we have been pretty successful. (Consultant)

Exposure to the programme functioning well and direct contact with the support worker helped promote confidence to refer patients. The lead team continued to promote the programme throughout its duration, ensuring that teams were kept informed about how it was running, including passing on patient feedback.

3.3.4 Introducing and managing patient transition to the programme

Men were generally given an initial introduction to the follow up programme by their consultant during a clinic appointment. They would then meet with the support worker or a CNS to be given more

detail. There was an expectation among staff presenting the programme detail that some men would find the IT solution and/or the workshop off putting. While this did not prove to be generally the case, the team did come across some resistance to these two aspects:

Some say, “oh, I can’t, I haven’t got a computer. I don’t like that, I’d rather still talk to you”. (CNS)

Some men have been a bit apprehensive about the workshops, which is to be expected. And I think we all thought that would happen. (Support worker)

There was evidence in the interviews of a development in the teams’ thinking and practice in presenting the project to men, to positively frame the programme and to address these issues, so that men were more encouraged to embrace the approach. For instance, practice changed to introducing men to the possibility of the programme early on in their cancer pathway; ways of explaining it changed to more clearly highlight its benefits, such that it is a more holistic system of follow up to address all of men’s needs; and pointing out that they are offered it because they are doing well:

And I think the things that I would have changed would be the way it was pitched to the patient right from the beginning. And I would say to somebody setting up this service, that’s key in getting people on board, on getting the patient on board, is how you sell it to the person. (CNS)

There was a shift from being tentative and giving men a choice about whether to sign up to programme, to giving a more limited choice:

The consultants are being a little bit more like, “If you don’t need to come to clinic, you’re not coming to clinic” (INT: OK). So they are starting to say to people, “You can either go on the remote tracker where you can follow yourself up or you can go onto telephone follow-up but you’re not coming to my clinic anymore. (Lead CNS)

The team also became more adept at presenting the workshop in a way that might be less off putting and more encouraging for men:

I changed my wording, I guess, in terms of, “this is going to be, you know, find some symptoms to look out for, for the future to keep you healthy, to prevent you from developing different problems in the future.” And then also I discussed it as a final appointment. I stopped using it as, “oh, and this is a workshop that you *can* attend”. This is, “your final appointment will be in the form of a workshop.” Kind of changed the way I sold it to the patients. (CNS)

3.3.5 Workshop

The workshop was a highly valued part of the pathway for those involved in its delivery (CNS and support worker). These healthcare professionals (HCPs) saw it as key to building necessary relationships with the men for successful Supported Self-Management (SSM):

I think they (men at the workshop) realise that we are approachable and that we’re available if they have questions or problems, particularly the ones who haven’t met us before (CNS)

The workshop was a key change in the work of these professionals, and necessitating a new way of working with patients and a new way of delivering information. The CNSs saw value in getting to know the men and having time to explain things to them. For the HCPs involved, early experiences of delivering the workshop were stressful, as a new way of delivering care in a different environment and the enactment of newly learnt skills of group facilitation and public speaking. The practice of facilitation proved challenging for nurses who are perhaps used to a more didactic form of

information giving and somewhat paternalistic approach to care; all involved felt these things improved with practice:

The workshops obviously was a bit of a learning curve. Going from being in nurse-mode where you want to make everything better for people and you want to give them the answers, and encouraging the men to think of the answers for themselves. That was a bit of a learning curve for me in the first instance. (Lead CNS)

So I can still remember that first workshop and I was absolutely terrified. I thought, 'oh, I don't know if I can do this', you know, twice a month. But now, I do the workshops and I don't even think about it now. And I just get up in front of the men and start chatting and it doesn't really even bother me anymore. So I think for that, for me, you know, it's been a massive learning curve for me, and I really enjoy them. (Support Worker)

The task of organising the workshop was a role for the support worker. This included booking the venue, organising materials, informing men about it. The workshop was purposefully small, to maximise interaction and thus learning benefits. This is in contrast to larger type of 'wellbeing event' often included as part of the Recovery Package (2), and existing in some of the sites for other cancer groups. Within this context, and with funding pressures, there were concerns about pressure from managers to increase the size of groups in the future.

Delivery of the workshop took the involved CNS out of the department, and necessitated her absence being covered by other members of the team. Whilst other members of the team covered their absence, one CNS was concerned whether the workshop seen as legitimate work by other team members:

I think with all the pressures on the NHS and, you know, who's doing what in the department it can also sometimes be seen like: "Oh, they're off on a bit of a jolly! They're not in clinic, they're not seeing patients" (Lead CNS)

The workshop represented a key moment in the man's journey through the programme, as it often marked an end of treatment phase and it involved an intense contact with HCPs and other men. The majority of the men who attended were positive about their workshop experience. However, there were also men who were less positive, some not finding it relevant to them in terms of information or support:

Well I felt very informed, and I felt relieved and I felt encouraged, and everything was quite positive, and it was a good thing to do. (Patient 6)

It didn't help me at all because, you know, compared to the other people that were on the programme at the time, you know, they had a lot more issues than I did. So I felt that it wasn't appropriate, applicable to me so much. (Patient 12)

Men most commonly valued the opportunity to share their experiences with other men, and often articulated this in terms of the reassurance gained from comparing one's own recovery with that of others and in finding out that side effects were normal:

Well what I found useful, I think, was just to hear what other people had been through and the sorts of things that were worrying them. And of course then you just compare it to your own concerns or worries that you may of had at the time. So there's a degree of self-assessment, if you like, about how you feel and understanding perhaps of how you might have felt and the reasons for it. (Patient 7)

So little things that was happening to your body you thought, 'oh, you know, is that normal or what not?' So the workshop helped that because by talking to some of the lads, they were having exactly the same problems as you, or similar, you know, so it did, it eased your mind a bit. (Patient 14)

Many men felt that the workshop had been facilitated in a way that allowed the sharing of sensitive issues and problems, although this was not the case for everybody:

Well I found it very good, or very positive that they were able to speak very frankly; they encouraged us to speak very frankly; and it was quite a strange feeling that it was conducted by women, but it was all men and, you know, there were men talking about their intimate sexual problems, and libido problems etc. But the women made us feel very comfortable about it, you know. (Patient 6)

there was lots could have been said but, I don't know, I just thought, 'what are we meant to say here?' I can only speak for myself but when you are in a group, rather than just seeing a nurse, men tend to speak less, in my opinion, it was a group of five men, they're not going to open up are they. *Interviewer: That's interesting. Did you openly discuss about any of your problems?* No way! Why would I? They weren't going to, the other guys weren't, so I wasn't. (Patient 23)

For some men the workshop led to action being taken on side effects that had previously been ignored:

Well to be honest, one of the things that nobody ever talks about is the sexual side of, the effects on your sex life of the treatment. It's probably something that they don't want to talk about when they're telling you to do one particular thing or another. You know, they'll mention it but, then you read about it on the internet but nobody really sits down and talks to you about it. And for men, it is a major part of their life. I think that probably that's why in this workshop they did spend quite a large section talking about and showing films about other men that have been through the experience, and how they coped with it. And I found that to be the most useful, sort of getting that out in the open. And for me, I followed up on after that, and that helped me overcome some of my concerns that I'd had. (Patient 18)

Men were asked specifically for their views on the lifestyle part of the workshop and whether it had led to them making any changes. The majority reported they did not feel the need to make any lifestyle changes as they were already doing the right things, though a small number of men felt the workshop had prompted them to re-evaluate:

I was coming from being in a good position so it didn't bother me at all, but I can understand that being there as a good point to raise. But in my case I haven't actually had to make much changes to be honest. (Patient 15)

I think it makes you, you know, really look at your life and your lifestyle to a certain amount. I used to be in the drinks industry and so, you know, I've always been involved in drink and what have you. But I mean it just made me really look at my lifestyle, if you like. (Patient 11)

3.3.6 Patient online service

The support worker was the key user of the IT service at each of the sites, using it daily and being responsible for entry and maintenance of patient information. Other members of staff, such as the CNSs, had less involvement with the portal and were not as proficient with it.

There was some degree of distrust of the IT among the support workers, following a number of minor problems regarding data within the system. This led the support workers to frequently double check information on the system, and to create back-up systems:

The main thing I would say is to get your own database set up straight at the beginning before you do anything else. Because I have a complete spreadsheet with every single patient on and when the PSA is due. It just mirrors the tracker. But I've also got on there, if they've come off their remote monitoring, when their appointment is. So I know they've got an appointment, so no one's going to get left. I have found that they've done their MOT, was there any issues on the MOT? And when the PSAs due and I highlight every PSA that's due for each month. Because even though you've got your tracker, I have had a patient just disappear off that at one point and alarm bells rang. So I would say always have a back-up. (Support worker)

One of the support workers reported concerns about security of the system:

I don't personally see that the tracker's that secure because basically the patients just get a username and a password to log in. And they don't have to confirm their name, they don't have to sort of, you know, put in their date of birth or anything like that. So firstly, you know, somebody could mistakenly be given the wrong information. And secondly the hospital number isn't checked against the patients details, so potentially the wrong patient's PSA could go wrong because sort of, you know, you could put patient A's hospital number and patient B's sort of information. And so, yeah, I don't like the security of the tracker and I have raised that with the project manager and the IT lead for the project (Support worker)

Among the men who were interviewed, only sixteen said they used the patient online service regularly. The men who did access it only used it to access their PSA results. The twenty-three men who were not regular users fell into one of three types. First, there were a number of men who had no access to a computer and had never intended to sign up to the IT system. Second, there were a number of men who had difficulty with the sign up process and did not persist or seek help:

And I couldn't get in the first time either, until we went to the workshop. And at the workshop, explained again how to do it, how to go in, and sent me another link afterwards. And it worked then with the next. And then after that, I couldn't get through no more so now I don't know what happened. (Patient 13)

Finally, there were men who had signed up to the portal but did use the system because they saw no benefit. This was mostly because they received their PSA results in another way: either they were happy to wait for the follow on letter from the hospital, or they actively sought their results from their GP surgery:

They write to you anyway, so they said, so it doesn't really matter. I mean if anything was wrong they'd obviously write to you and tell you. So, you know--- so I'm not bothered about that. (Patient 9)

The majority of those who did use the system found it relatively easy to navigate. A couple mentioned liking the graph feature; and one was pleased with ease of messaging.

One man highlighted that infrequent use could result in difficulty in remembering how to use the system:

I know you have to find your way around these things and you do get familiar with them if you use them daily but I probably use it once every six months. And I suspect everyone else is about the same. So you don't get familiar with it. It's something that you always have to sort of learn anew each time you approach it. (Patient 7)

In terms of improving the IT system, one man did not wish to receive a letter about his PSA result as well as being able to access it online and a couple of men mentioned that they would like to be able to have other test results made available through the system as well.

it would be nice to be able to include, rather than it just being a way of monitoring the cancer, if you're treating the whole person, it would be useful for me if you could get those other blood tests put into the system, so that you know, you're not just saying "All right, you do this for your cancer, and then you do something else for all your other ailments." Because I think you know, as the NHS, they should be looking at people as a whole and making sure that they're not getting other ailments and things. And you know, if there's one thing where they've got you on the system and they've got you actually working to monitor your health, then they could make it easier for you to do that by adding other things in, other blood tests and things like that, without you having to put it in manually like I do at the moment. (Patient 18)

3.3.7 Health MOT

Men were asked to complete a Health MOT form, a version of a Holistic Needs Assessment (HNA), at each PSA review point, which they could do either on-line or as a paper version with return by post. Completion was discussed at the workshop, when men were asked to fill in their first one. The rate of completion of the Health MOT was lower than expected, and quite an amount of extra work was consequently put into increasing completion, including support worker telephone calls to individual men.

There was a lack of consensus among clinicians about the necessity of completion, from desire to somehow make it compulsory, to seeing it as individual choice within the context of self-management.

And I think it should be compulsory. I think there should be a way that if that doesn't get filled in, then they don't get their results or something because that does worry me because if we don't, I mean you can have a PSA that's normal but the disease has progressed. (Lead CNS)

But really it's up to them whether they want to do it and I don't think that is the point of the project. It's called supported self-management. I don't think it's really, you know, telling them off if they haven't done it really. It's a choice thing. (Support worker)

In addition, the response format (yes, no, discuss) to questions on the Health MOT caused some confusion both for men completing the form and for staff interpreting the response. Uncertainty led to some follow up of response where the man had indicated the presence of a potentially important symptom but had not indicated that discussion was required:

say they've had symptoms for years and years and years, say for instance, bone-pain, they tick 'yes' but they don't tick 'discuss'. And it might be that they've had bone pain for twenty years but because they've got arthritis. Sometimes that can be, you know, you see a 'yes' for bone pain but they've not ticked 'discuss' but you're thinking, 'Well, I really need to ring that man because, you know, I'm not happy'. So sometimes that can be a bit confusing from our perspective, I think. So even though they don't tick 'discuss' sometimes we do ring them just because we want to be sure in our mind that there isn't a problem or an issue that, you know, we're not addressing (Lead CNS)

Interviews with men helped to throw light on the matter of Health MOT completion rates. Several men were not familiar with the Health MOT at interview, and/or did not remember completing one at the workshop. In addition, some men found the Health MOT a useful tool and others did not. Of those who found it useful, some valued the extra level of monitoring and the reassurance that it gave, and others valued the prompt to reflection:

It does trigger in your mind, oh, was I feeling like that? So it does make you go through it a bit. I mean things can creep up on you without you realising can't they? So it does give one the, what shall we say, the incentive to think more about your everyday health. (Patient 25)

However, other men saw no need to complete the Health MOT as they had no problems to report, some men pointing out that they would report any problems directly to the team anyway:

Interviewer: Did you find it useful?

Respondent: Not really because I had nothing to write down on it. (Patient 37)

I guess the only thing is personally I'm not one of these people that sit back and put up with things. If there was something wrong, I would message [the support worker] anyway. (Patient 18)

Finally, many of the men concentrated on the PSA result as the main indicator of wellness and so were less concerned about the need for the Health MOT for detecting problems.

3.3.8 Messaging and help seeking behaviour

A central premise of supported self-management is that men will self-monitor and will feel able to approach their clinical team if they have any worries or notice any changes that might be significant, having been taught what these are. Men in the programme are able to contact the team by telephone or by secure messaging within the patient online service. The support worker is first point of contact for messages and who triages any issues that they are unable to deal with to the CNSs. One support worker did note that the ability to record the detail of any response to telephone calls or messages on the IT portal would be helpful.

The team reported that men commonly contacted them regarding their PSA checks, with problems with the online service, and with symptoms. There were a number of instances discussed when men had appropriately self-referred for problems, although there was also an awareness of men who had re-entered the hospital system by other routes:

We've had a couple that have let us know that they've either had haematuria or blood in their motions via the e-mail system or via the 'phone. And so we've made the relevant referrals from that. So it's great that those people have contacted us in between times and not just waited until their next review was due. So it shows that the system's working (Lead CNS)

There was evidence that men were individual in how they used and viewed the ability to message their clinical team:

Like so, each individual man will want sort of a different relationship. Some of the men will just want to see us at the workshop and move on and that's fine and they can sort of deal with everything then. Other men sort of ring us up every couple of weeks, just to say how they're doing and that sort of thing. So I think it's a really individual thing. (Support worker)

The majority of men reported that the clinical team were approachable and accessible, and that they would get a good response:

Very supportive actually, you know, and encouraging you to make sure that you 'phone if you've got any concerns. Yeah. You felt you've got a friend on the other end of the 'phone. (Patient 5)

I've had total confidence in the relationship with them, in that if I did have any need or have any issues or cause for concern, I could speak to either one of them, and I would be totally 100% confident that the issue would be resolved one way or another. (Patient 29)

From the men's point of view, part of self-management is knowing when help is required and deciding who to call on. Men were therefore asked about their help seeking intentions and behaviours. Mostly, men intended to call on the clinical team if a problem was perceived to be prostate related (a PSA rise; key signs mentioned at the workshop; side effects of treatment). Most men were not, however, expecting support for broader issues from the team, and were likely to go to elsewhere (if at all) for help with physical problems not thought to be prostate cancer related and for emotional, relational, and financial problems. In anticipating seeking help from the team, men sometimes recalled the support worker's name, but sometimes reported that they would approach the CNS.

Men in the comparator group also reported that they had CNS phone numbers and would phone if there was a problem.

However, help seeking decision-making was not always straightforward for men, particularly where symptoms of other co-morbidities or age related issues could be confused with indicators of recurrence of prostate cancer:

I was always on the lookout for indications that the cancer had spread, and I know that the most likely spread is to the bones. So I was perhaps over-sensitive to aches and pains. You know, at my age you can get aches and pains fairly easily. So perhaps one is self-diagnosing all the time, and then perhaps one is, yeah, over reacting to a slight backache. You think, 'Oh my word!' And I had some shoulder and neck problems, some sort of a nerve which had seized up. And I was quite worried at that time, because I thought, 'Well, goodness me, you know, is it the first stage of a bone cancer'. (Patient 20)

I've got kidney problems as well. My kidneys are on their edge of the limit. Difficult to assess the situation, if you have got problem with wee or something like that, I can maybe associate with the kidneys. Don't think about maybe prostate coming back. (Patient 13)

Putting this help seeking in context, while one of the premises of the programme and of cancer survivorship care is that men have unmet needs, this is a group of men who have been selected because they are considered stable and well enough to be monitored remotely and whose side effects have been remedied to an acceptable level. The men interviewed showed a great deal of acceptance and self-management of side effects. This incorporated a general approach to life, an approach to treatment and cure, an acceptance and rationalisation of side effects, and development of day-to-day ways to deal with any problems:

I feel okay and I've got no side effects apart from the flushes and, well yeah, I just lead a normal life. And I don't really honestly give it much thought. I don't sort of let it get me, you know, the thought of having cancer sort of weigh heavy on me. I just try to lead, I lead a normal life and don't think about it. (Patient 19)

And if you think about it, that's the most important thing, you know, that they've sort of rectified the prostate cancer side of it. The collateral damage is something you've just got to accept and I certainly have. (Patient 38)

You develop a strategy for dealing with the way you are and you just then get on and deal with it. (Patient 5)

I did not have any specific treatment for the bladder. And my average time going to the toilet at night is twice. Sometimes it's once. Sometimes three. It depends on what you drink of course. I control what I drink in a day. Now, I drink, very consciously, around about 1500ml a day. (Patient 21)

3.3.9 Virtual clinics

The virtual clinics were valued by the CNSs as an efficient way to monitor men who were likely to be well and stable:

It's time saving and quick and easy, compared to traditional clinic and seeing that many patients face to face, so obviously that's a positive. It's just an easy way isn't it, you know, you sit down, go through them, everything's okay in the majority of cases, you know, and the support worker will obviously send the letters out to patients and GPs. It's just quite a slick system. (Lead CNS)

While efficient, it was noted that it could be difficult to find the time to run the clinics:

Trying to find time for the nurses to sit down with you and go through those results which can be tricky. They are so busy. (Support worker)

As noted earlier, there was disagreement about whether the support workers should be given the responsibility of checking PSA results. This resulted in variation in the way sites organised their virtual clinics; in three sites, the support worker and lead CNS would allocate time each week to sit together and check the PSAs, while in one site the support worker was given responsibility for

checking PSA results and triaging any queries to the CNSs. Easy access to help and support was important in the latter case:

I review all of the blood results myself. Basically because, you know, I've got really used to what's okay and what isn't now. And obviously if it's risen and I'm worried about it or it's, you know, above the boundaries that the project's set, I'm sitting next to the two nurses now, I work in the office with them, so I can just literally ask them if that's okay or what to do next (Support worker)

While the CNS was involved in the confirmation of PSA results, the support worker completed all the related administration. This could be quite time consuming, particularly where the system did not update personal information and where there was mistrust in the system to pull the correct result:

It does take quite a while. Because the addresses on the tracker don't update alongside the hospital records one, you know, say for example someone moved house, they'd obviously tell the hospital but it wouldn't change on the tracker. So for every patient onto our hospital computer system, and I check their address. I always check that the PSA that's come up on the tracker system is the actual correct one for that patient. So it's a lot of, you know, sort of double-checking and then printing out the letter and writing the PSA result on myself because that doesn't come up for some reason. Yeah, so, you know, it's a long process and quite fiddly. And we don't trust the tracker a massive amount, I think that's the big problem. (Support worker)

There was some concern that sitting at a computer was not seen by other members of the team as legitimate work for a CNS:

it's also just making the department aware that, you know, this is important for us to do, even though we're sat at a computer, it might not look like we're really doing anything but we are, we are doing something (Support worker)

3.3.10 Sustainability and spread

Implementation was externally funded for the development and evaluation phase of the project. All sites were keen to sustain the programme beyond the period of initial implementation and had sought, or were in the process of seeking, continuation funding. While all teams were hopeful that funding would be secured, there were some anxieties about this within the current financial climate. At this time, there was also some concern about the continuation of the workshop in its proposed form, with questions being asked by managers external to the clinical team about the numbers of men in each group.

There was recognition of responsibility for sustainability of projects which have initial start-up funding, and recommendation that such projects should have assurances of sustainability early on:

My advice to any of my colleagues would be, prior to making that agreement and signing that contract, we should at that stage, before we commit, ensure that we have buy in from the organisation that at the end of that twelve months, we are going to pick up the bill and keep funding that post going. It was one thing that I was kicking myself for the whole time, thinking I wish I'd written this business case twelve months ago. Because the organisation was in a place of saying to me, "well, you didn't come and ask us in the first place about whether we'd be prepared to fund this post in the long run". I'd just seen, you know, the opportunity of having the post funded and thought, 'great, let's go!' But actually we should have probably taken that stop, taken at the first stage before we agreed to sign for the twelve months funding, and determine the organisation that yes, we've got that buy in, we've got that support, the business case is written and, you know, the funding will be allocated in the year that it's needed. (Non-clinical management)

Among the issues being debated through this process was the amount and source of funding in relation to the programme, with the shift to remote rather than face-to-face monitoring:

Even though our clinics are over booked and it is very complicated how you actually get paid, the general concept is if you see somebody in clinic you get paid for it, whereas if you don't see them you don't get paid. And there's the kind of revenue loss which is very boring but it's, you know, part of the project. So we've had to speak to all our commissioners to try and get it secured as a telephone follow up tariff. Because we recognise that you shouldn't get the same as them coming up to hospital visit but it still is working, it still is overseeing. Although it's dull, that is kind of what pays the bills. (Consultant)

All sites were interested in the potential to apply the follow up care model more widely: to other prostate cancer groups (such as active surveillance patients), other urology patients, other cancer groups or other long term conditions. One team had adapted the workshop format to be used for men at the pre-treatment stage. There was, in fact, some concern about the inequity of delivering a new option of follow up to only one distinct group of patients within a department or Trust. Additionally, there was consideration of how to further develop the support worker role within the team, for instance in the management of other urological cancer patients.

4. CONCLUSIONS

Embedding the programme

The programme can be successfully embedded into a urology team and, within the current climate of increasing numbers of cancer survivors, is valued as an effective and sustainable model of follow up care provision and a robust alternative to face to face clinic follow up.

The programme has operationalised the main components acknowledged to underpin self-management support: risk stratification to tailor support to need; personalised assessment and management plan; tailored information that enhances knowledge and a partnership relationship with their health professionals which enables self-management (9). We have demonstrated that the programme as perceived by the teams and patients enables these four different features.

Value of the programme

The programme is viewed by staff as enhancing the safety of follow up care when compared to a system of overloaded clinics where there is a greater likelihood that PSA tests may be missed, appointments may not be timely, or patients may be lost to follow up. This is achieved by means of a dedicated worker to ensure that men comply with the follow up regime.

The programme is also viewed by staff as enhancing the quality of care provision: more knowledgeable and informed patients who have access to a dedicated support worker who is much more readily accessible to deal with men's holistic needs. The CNSs and support workers in particular value the holistic and person centred approach to the pathway.

The programme was perceived by the teams to change the nature of clinic workload, allowing consultants to give more time to patients with complex needs.

Men were generally satisfied with the programme and valued, in particular, the reassurance given by easy access to support if and when it is needed. They considered the programme as a legitimate development, within a pressured health service, for men who were doing well following treatment.

The addition of the support worker within the nursing team released CNS time.

Introducing the programme and driving it forward

The key project champions are the lead clinician and lead CNS, with the support worker becoming a champion by example.

There is a need for continued presentation of the programme to team members and management colleagues. The programme team have direct reports of patient satisfaction but the nature of programme means that consultants no longer have contact with patients they refer to the programme. Lead teams should keep others well informed of such reports..

The pathway represents a behaviour change (referral to the programme), but also a shift in thinking (delegation of care of patients to other staff) for the wider team. The relinquishing of care of patients to others requires trust in the new system. Some team members take longer to assimilate these changes than others. Sites where non-face to face and or/nurse led forms of follow up are already implemented may be more receptive to this new form of follow up and may find this shift in thinking easier.

Early and detailed engagement of Trust IT and pathology departments should be undertaken, to avoid delays in setting up required systems.

The programme is a new form of care for most patients; the evaluation has highlighted ways to present the programme as a positive change.

Screening and referral

The work of identifying and referring patients to the programme was embraced by the majority, although some clinicians may need more encouragement than others. Confidence among clinicians to refer is facilitated by: continued work by the lead team to promote the programme (e.g. this may shift from informing about project goals to passing on patient 'stories'); personal contact with support worker; and exposure to the programme and its benefits.

Cultural change

The programme represents a behavioural and cultural change for the CNS leading the project. They may, for instance, acquire new skills, such as line management and project management. While the support worker role is a support for CNS and provides a more efficient way of dealing with some tasks, there is a need for letting go of tasks once trust in the support worker has been established. There is also a change in the way the CNSs view

New roles and ways of working for nurses, (such as running workshops and virtual clinics, as opposed to running clinics or ward work) may not be regarded as legitimate by the wider team and management and may cause tension, which needs to be addressed,

Support worker role

The introduction of support worker to the team was overwhelmingly positive, but requires careful training, supervision and aptitude of the person in the role, and a supportive and flexible team to maximise the value of the role.

Workshop

The workshop was considered a fundamental part of the pathway for those staff working closely with patients and involved in delivering the workshop.

Delivery of workshop involves learning of new skills for nurses and support workers.

The workshop is a positive experience for most men, in particular, the opportunity to compare experiences and symptoms allows men to gauge where they are in relation to others, which helps them make sense of how they are doing and to normalise symptoms; this contributes to wellbeing and ability to self-manage.

However, some men find the workshop format too challenging.

In challenging financial times, a strong case may need to be made for the value and format of workshop, particularly in a Trust where patient events are run in a different form for other patient groups.

IT service

The IT service was recognised as fundamental to the efficiency of the programme. Support workers became experts in using and managing the system.

There had been some lack of confidence in some aspects of the IT service, though these were passed on and addressed by the IT Team. The responsiveness of the central team to problems and queries was valued.

Use of the IT service was not universal among men on the programme and was mainly limited to checking of PSA results. Because of low levels of IT literacy in this age group, a paper based system was tailored for those who did not wish to engage with the IT. Access to PSA results from other sources (confirmation letter from the programme team or directly from the GP) may be discouraging its use. This and infrequent use of the portal, indicates the value in reinforcing computer use over time and making continued and easily accessible support available. A more focussed evaluation of the IT service has been undertaken separately (see Technical Report 4) which confirms most of the conclusions drawn from the interviews reported here.

Health MOT

Understanding of men's perception of and use of Holistic Needs Assessment (HNA) in cancer survivorship is limited. Although this and other work (10-12) has begun to shed some light on these matters, more understanding of issues of design and execution of this type of tool is needed.

While HNA undoubtedly has a role at key points in care, such as transition from treatment to follow up care, it is not clear, nor is there consensus among clinicians, about whether repeated HNA is needed at multiple points during the follow-up care phase. The value of the HNA alongside PSA testing in identifying potential recurrence during follow up is not known, particularly where men have been trained to look out for key signs to report and have easy access to HCPs by telephone or messaging. There is something of a paradox between a self-management approach and mandatory HNA completion. There is also a lack of clarity regarding the role of HNA alongside the currently developing field of PROMS (Patient Reported Outcome Measures) completion, which may be the preferred method of some clinicians.

Current Health MOT response categories lead to ambiguity in interpretation of responses by HCPs and to potentially unnecessary follow-up. Currently, sites will need to find what they are comfortable with in terms of requirements of completion and put in work, if necessary, to achieve that level of completion.

Virtual clinics

Virtual clinics are an efficient way to execute review of patients who have been previously assessed as well and stable. However, teams introducing this approach need to be mindful that

efficiencies can only be realised if the support worker is trained and supervised effectively and the CNS works in a way that does not duplicate functions of the support worker.

Sustainability

While implementation was externally funded for the duration of the evaluation, Trusts were committed to continuing the programme model, though there was ensuing debate about the format of funding. There was also recognition of the value of the model to other cancers and other conditions.

5. REFERENCES

1. Frankland J, Brodie H, Cooke D, Foster C, Foster R, Gage H, et al. Follow-up care after treatment for prostate cancer: protocol for an evaluation of a nurse-led supported self-management and remote surveillance programme. *BMC Cancer*. 2017;17(1):656.
2. Independent Cancer Taskforce. Achieving World-Class Cancer Outcomes. A Strategy for England 2015-2020. 2015.
3. Batehup L, Cranshaw G, Lowson E, Lynall A, Martin F, Simmonds P, et al. Improving patient experience of cancer follow up: redesign and evaluation of adult cancer aftercare services for breast, colorectal, and testicular patients, at University Hospital Southampton NHS Foundation Trust. National Cancer Survivorship Initiative Conference: 'Exploring the challenges and opportunities of integrating cancer survivorship care' 16.11.12; London 2012.
4. Batehup L, Porter K, Corner J, Simmonds P, Heather Gage H, Williams P, et al. Patient triggered follow-up with support for self management: a novel approach for survivors of testicular cancer. NCRI Cancer Conference; Liverpool 2014.
5. May C, Finch T. Implementing, Embedding, and Integrating Practices: An Outline of Normalization Process Theory. *Sociology*. 2009;43(3):535-54.
6. QSR International Pty Ltd. NVivo qualitative data analysis Software. 11 ed 2015.
7. Barbour E. *Introducing Qualitative Research*. 2nd ed. London: Sage; 2014.
8. Department for Communities and Local Government. The English Index of Multiple Deprivation (IMD) 2015 – Guidance Gov.UK 2015 [
9. DH Macmillan Cancer Support & NHS Improvement. *Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision)*. London; 2013.
10. Snowden A, White C. *Assessment and care planning for cancer survivors: a concise evidence review*. London; 2014.
11. Natalie Doyle, Richard Henry. Holistic needs assessment: Rationale and practical implementation. *Cancer Nursing Practice*. 2014;13(5):16-21.
12. Young J, Cund A, Renshaw M, Quigley A, Snowden A. Improving the care of cancer patients: holistic needs assessment. *British Journal Of Nursing (Mark Allen Publishing)*. 2015;24(4):S17-S20.