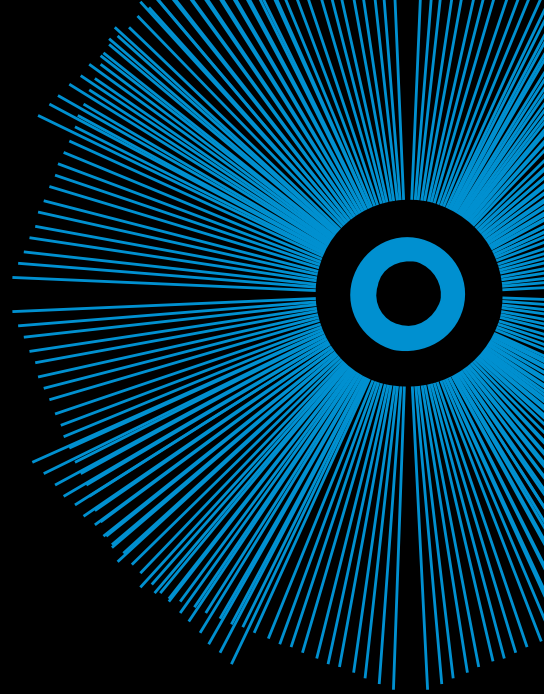




Shine



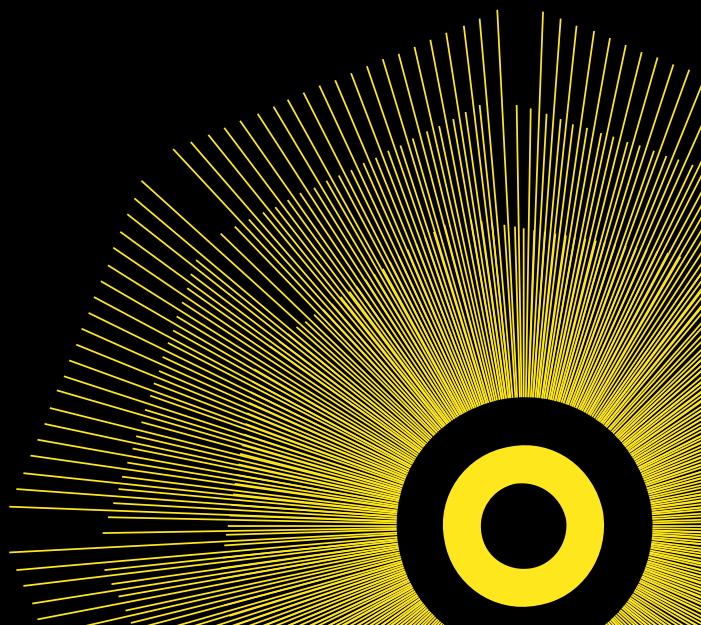
Shine 2012 final report

POP Home Project

Cambridge University Hospitals NHS Foundation Trust

December 2013

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Part 1. Abstract

Project title: POP Home Project

Lead organisation: Cambridge University Hospitals NHS Foundation Trust

Partner organisation:

Lead Clinician: Rohna Kearney

Pelvic organ prolapse (POP) is a common condition with a lifetime risk of prolapse surgery of 19%. Pessary management is offered to women with symptomatic prolapse as an alternative to surgery, which involves attending clinic for pessary changes every six months. Many women find this inconvenient and uncomfortable thus stop pessary use and choose major surgery. In North America women change their own pessaries, reducing the need for hospital attendance and enabling them to individualise how often they change their pessaries. The POP Home project set out to develop a teaching programme for women treated at Cambridge University Hospitals NHS Foundation Trust (CUH) to firstly understand whether pessary self management (SM) was something that women wanted to learn, and to understand whether it would improve patient experience and decrease likelihood of surgery. We were also keen to see whether SM would be a way of releasing outpatient capacity through reducing follow up attendances. The project has the potential to be rolled out to community services for GP practices to use.

A focus group of pessary users has been used to help design the service. The group met to discuss the teaching process, timings of follow up phone calls, review the leaflet and to share their experiences of using a pessary. The gynaecology department have also reviewed the patient's leaflet and the patient pathway, which was important to make sure the pessary SM project worked alongside existing pathways within the hospital.

Patients with a ring or Falk pessary were given the option to learn self management, and were taught by a women's health physiotherapist at CUH. A telephone call at two weeks, one month, three months and six months was carried out to check the women's progress. A telephone number and email address was also provided if the woman experienced any problems in the interim period. A patient information leaflet was designed and an online tutorial including a video has been published on the hospital website for our women to use once home.

A patient satisfaction questionnaire was designed to capture patient's experiences on the pathway of six monthly pessary changes by a hospital doctor/GP and on the SM programme. Demographics were collected of women who opted for SM and women who declined the service. Reasons for declining the service were also recorded.

Throughout the project we have had two different patient groups to draw on; women who are already under doctor-led management (DM) for pessary use and women who were referred into the service. We have seen an interesting variation in uptake between these two groups. Only four patients under DM opted to switch to SM when we sent out an invitation at the start of the project. The remaining women (48) were recruited from clinic or referred from GP or physiotherapist. This suggests that women who are new to pessary management are more likely to opt for SM than those that have been using pessaries for some time, or that women who are already under DM care are more likely to opt for self management if they discuss the option with their doctor in clinic, rather than responding to a letter.

A challenge of the project was that the patient referral rate was slow initially. Therefore we increased our referral sources to local GP surgeries and other health care professions. The

service was advertised with regular newsletters to GP's, posters, business cards for doctors to hand to patients and by attending GP specialist interest group meetings to talk about the project. The project won first prize in the patient dignity and experience category at the Health Enterprise East Awards and has been short listed for an Advancing Health Care Award in the prevention is better than cure category (winners announced April 11th 2014). This has helped promote our service.

Women who were under DM were telephoned to explore reasons for not wanting to try SM. Most women perceived they would experience physical barriers (15). Other reasons included women preferred DM (8), perceived pessary changes would be too difficult as GP/nurse had struggled in the past (6), disliked the idea because of the area/nature of intervention (5), thought it would be too painful (4), thought they were too old (4), had emotional barriers (3), had poor cognitive ability (3), could not travel to the appointment (2), or had difficult personal circumstances (1) (*five women gave multiple answers). Now that we have patient satisfaction data from patients in the SM group we can use this to alley some of these fears that women might have.

The programme has shown women are able to self-manage vaginal pessaries. Patient satisfaction was higher in the POP Home group. SM reduces hospital appointments, frees capacity and reduces financial costs to the hospital and wider health economy.

Part 2. Quality impact: outcomes

Our primary outcome measure has been patient experience. As part of the project we have evaluated the experience of patients on a doctor led pathway against those who are self managing via a patient questionnaire. A summary of some of the key findings from this evaluation is outlined below, and a full summary can be seen in appendix 2:

Outcome measure	DM group	SM group
Finds the service convenient	81%	95%
Fells they can access help if they need it	73%	100%
Feel supported in their pessary use	83%	100%
Find pessary changes comfortable	53%	90%
Plan to use a pessary in the long term to manage symptoms	71%	100%

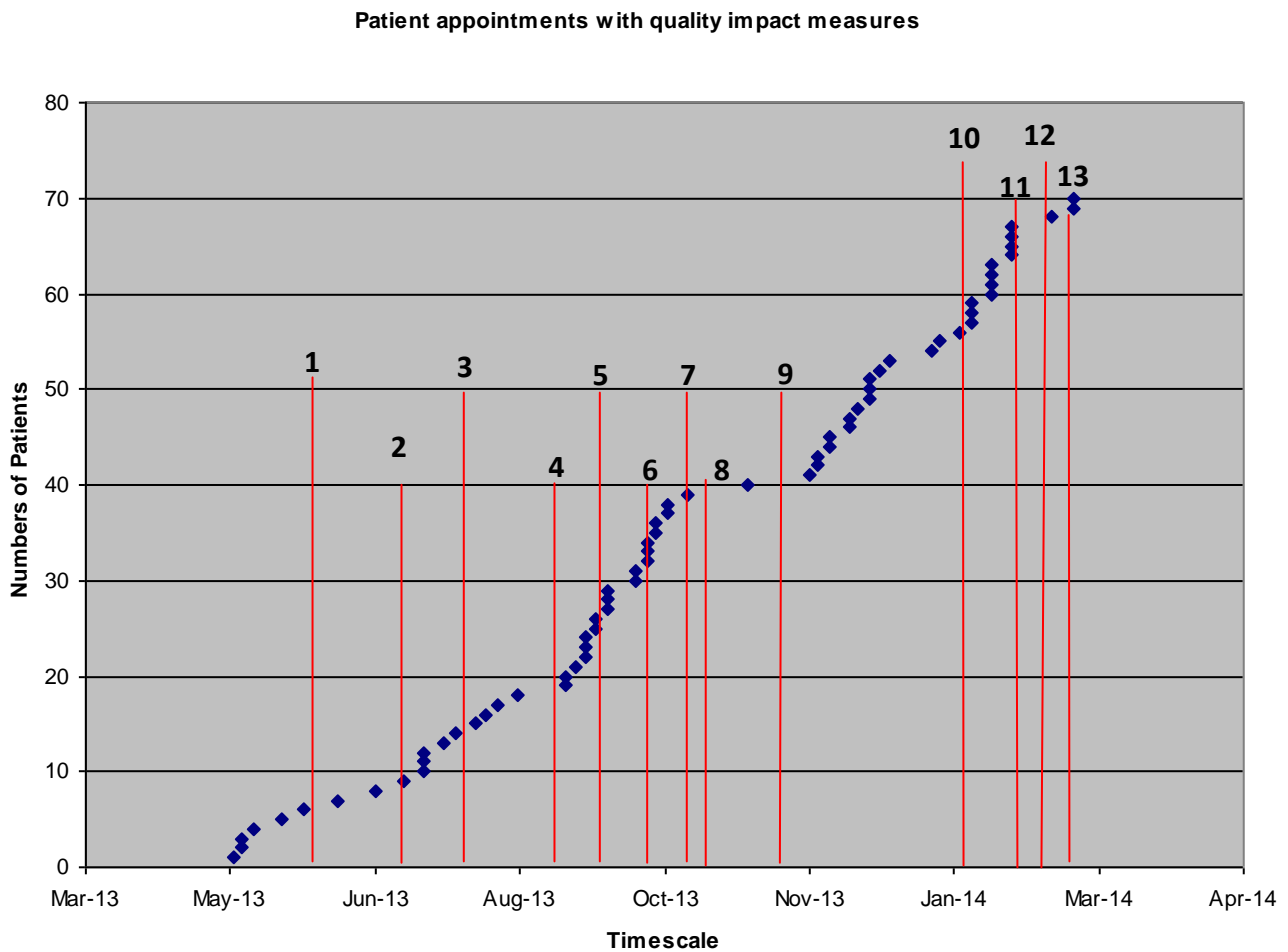
We have seen a marked improvement in patient experience in the self-management patient group. One of the most interesting findings is the increased comfort that self managed women are experiencing with pessary changes (90% of women report that their pessary changes are comfortable in the SM group against only 53% of DM women.) We feel it likely that this is connected to the fact that 100% of women self managing for longer than 3 months report that they plan to continue pessary use in the long term against only 71% in the DM group. As the only alternative to pessary use in the management of pelvic organ prolapse is major surgery, it is of significant value to patients and the wider health economy to have found that SM appears to reduce the likelihood of surgical intervention. Many women in the SM group report that they only use their pessaries intermittently, for example if going on a long walk, and value that self-management allows them to personalise and take control of the management of their prolapse symptoms. Patients have reported that they feel more empowered and in control through self management.

The response rate for the POP Home questionnaires was high at 83%. Questionnaires were chosen as a method to capture results as patients can remain anonymous. Due to the sensitive nature of our project this was essential for data collection. Patients were also invited to share their stories of learning to self manage their pessaries to enhance our understanding of the impact of the project (see appendix 2).

In the last 9 months of teaching women self-management we have not seen any adverse effects.

100 appointments slots have been released, increasing capacity in our Urogynaecology clinics.

Due to the slow up take of the service we needed to be proactive in trying to recruit new patients. Below shows a graph of patient referrals plotted against project activities to show the effect on patient recruitment.



Key:

1. Focus group
2. Invite letters to existing patients
3. Invite letters to existing patients
4. GPs given open referral access to the service
5. Invite letters to existing patients
6. Physiotherapist changed working days*
7. GP Newsletter
8. Awarded Health Enterprise East Innovation award for patient dignity & experience
9. Attended local GP special interest group to present outcomes of project so far
10. GP Newsletter
11. Started to present findings at MDT meetings
12. Physiotherapy Presentation
13. Patient video online

*The physiotherapist was employed to work two days a week, and at the beginning of the project these two days didn't correspond to the days that urogynaecology clinics ran. When the physiotherapist switched days we could offer a 'one stop' service where patients went straight from clinic to learn self management. We found an increase in patient numbers after this change.

Part 3. Cost impact

The key measures that we have used in understanding the cost of providing a doctor led pessary management service are:

- Staffing costs in clinic
- The cost of replacement pessaries
- The tariff cost that commissioners pay for an outpatient follow up appointment

This has provided us with two separate costs: one to the commissioner (£168 per patient per year) and one for the hospital trust (£140 per patient per year). These costs can be calculated as savings for each individual patient that goes over to self management from doctor led care.

The cost of providing the self management service can be related directly to the cost of the physiotherapist or nurses time in teaching the patient. We have calculated that each patient will take approximately 1 ½ hours to teach and then follow up, which equates to a one off cost of approximately £30 per patient. This is significantly lower than the cost per year to the Trust of doctor led care. Based on a cohort of 50 patients moving to self management, we have summarised below the cost impact of this:

	Cost to Trust	Cost to commissioners
Doctor led care	£7,000	£8,400
Self management	£1,500	£0.00
SAVINGS	£5,500	£8,400

The opportunity to scale these savings up across the region is significant- as Dr Foster suggests that there were over 6,688 hospital clinic attendances across the East of England last year for pessary changes. Based on local practice this would suggest approximately 4,000 individual patients using pessaries in the region, which doesn't take into account the majority of pessary patients which are managed via GP practices. So you can see that the opportunity to release savings if self management were to become embedded within the region is significant. Even if you were to take a very conservative estimate, and only base savings on the direct tariff cost to the commissioners of those 6,688 attendances in clinic the opportunity is in excess of £500,000. For this reason, we are now in discussion with local commissioning groups about how we can best capitalise on the learning of this project and roll self management beyond CUH. We have submitted an application to the Widening the Impact fund held by the Health Foundation to enable us to roll out training to healthcare professionals across the region in enabling their patients to self manage.

Part 4: Learning from your project

The expected benefits and outcomes in our initial application were to deliver:

1. A robust assessment of patient experience, enabling us to understand whether SM represents an improvement to them.
2. An education and support package that can be given to patients both as part of this project but also rolled out nationally once proven to be successful.
3. Clear clinical outcomes data reflecting any changes resulting from the new pathway.
4. An economic assessment for the new SM pathway.
5. The release of approximately 200 outpatient appointments per year.
6. A 'toolkit' for other Trusts who may wish to adopt this practice.

We feel we have delivered on all of the desired outcomes above. Based on our current patient numbers we have released approximately 100 slots year on year, however as the uptake to SM is mainly in the newly referred patient group we expect to see a similar number of patients move onto SM each year. This will mean that within the next 12 months we are likely to have reached our target of releasing 200 clinic appointments.

In addition to our planned outcomes, we have also seen an unexpected benefit of increasing our understanding of how women feel about gynaecological issues. Having the time to dedicate to teaching, the running of the focus group, and the telephone follow up calls, has enabled us to explore in depth the stigma that can be attached to gynaecological issues as well as women's attitudes towards and understanding of their own bodies. This has been a thought provoking process, and has significantly enhanced the clinical teams understanding of patient's wishes, needs and motivations. This has started to make us think about other projects we could run that focus on teaching women about their anatomy and how to prevent injury for example in childbirth.

Teaching pessary insertion/removal was a new skill for the therapist; we are not currently aware of any other physiotherapists nationally who are trained in pessary management and so this is a completely new skill set that can be developed into other AHP roles. It was found that learning alongside the patient enhanced this skill. For example one patient reported a pessary held in the correct position in the hand resembles a "taco shell." This imagery has since been used to help other women remember how to hold the pessary. Confidence in teaching SM has also grown with a greater volume of patients, as the therapist was frequently asked "how many women have been able to do this?" or "has this happened to anyone else?" There are some women who are unable to SM for reasons of dexterity, however as more and more women were successful this helped the physiotherapist to understand that this is an expected outcome and not a reflection of the quality of the teaching. Recruiting a physiotherapist to this project was not something that we had originally considered, as we had initially seen this as a specialist nursing role. We believe however that by having a physiotherapist, a role which traditionally focuses on rehabilitation and not medical intervention, at the heart of the service we have been able to develop something which is truly focussed on empowering the patient to manage their own condition away from a healthcare setting.

A challenge of our project was referral numbers remained low at the beginning. We found a brand new idea takes time to get momentum.

The physiotherapist only worked two days a week, which limited the speed at which we could raise the profile of the project internally. The physical environment of where our clinic was held meant integrating with other members was difficult because of a limited number of clinic rooms being available. This sometimes meant that whilst we aimed to offer a 'one stop' service where women could be taught SM straight after finding out about it in clinic, there wasn't always a room available for us to offer this service and so they would have to come back. A further barrier of the project was the reorganisation of our local primary care setting.

This has delayed some of the discussions that we wanted to have earlier on in the project with commissioners about sustainability of the project.

We did not market to external stakeholders until 6-months into the project because we had expected more of our existing patients to want to try SM. Once we did we noticed an increase in referrals. We also could have asked for feedback from our Urogynaecology team earlier on about what they were looking for to see if our service has been effective. We have since asked this question to our team and made adjustments. For example a registrar asked how often patients were taking the pessary out. We now include this question at our 3-month telephone call and update the team regularly.

Part 5. Plans for sustainability and spread

Local sustainability has been addressed by involving a physiotherapist already working for the trust to teach pessary SM. Nurses on the ward will also be able to teach patients SM. Nurses and the physiotherapist have been approached to organise shadowing opportunities to assist in their learning how to teach SM. Patient referrals have been averaging 6.5 per month and 8.7 appointments per month (the difference in numbers is because patients return for pessary resizing if the pessary falls out). This should not impact on the staff's current case load. Follow-up telephone calls will be minimised. Patients will be given the same email address and a new telephone number to call if they are experiencing any problems. Additions to the patient information leaflet and information on the web site has been changed. Replacement pessaries will be arranged by the nurses who are teaching SM.

An abstract has been accepted for an oral presentation for the 2014 UK Continence Society conference to present the project. Our findings and experience will be shared at a national level. We feel this is the best national conference to share our experience as the conference is attended by Urogynaecologists and other health care professionals. The conference is patient orientated and has a multidisciplinary team atmosphere. Professional groups have approached the POP Home team to present the project to a group of physiotherapists in Cambridge and in Norwich in February and June 2014. The Primary Care and Public Health Conference has also approached the project and has invited POP Home to speak to 6,000 GP's and allied health professionals in Birmingham, May 2014. We have also submitted an abstract to the BMA patient information award and entered the video into the patient information self-care category. An abstract is being developed for the BMJ Quality and Safety Journal for publication this year. We have also submitted the POP Home project to the International Urogynaecological Association Conference in Washington, July 2014.

We were approached in October 2013 by Poringland GP Practice in Norwich to discuss ways their patients could access our service. Due to clinical governing issues the project was only able to offer teaching to patients if they wished to travel to Addenbrooke's Hospital. However the GP surgery thought patients would decline the service because of distance. In May 2013 a physiotherapist from Jersey was in contact regarding teaching pessary SM. As a result of this, the information leaflet has been published on the interactive Chartered Society of Physiotherapists forum.

We are currently in discussion with our local clinical commissioning group about how to spread SM beyond CUH, and have applied to the Widening the Impact fund held by The Health Foundation to enable us to do this. Many patients using pessaries are being managed by GPs and so the impact of promoting SM on capacity in primary care could be significant. We are keen to share our learning with GPs and commissioners locally and to consider what might be the most effective teaching models to ensure that the maximum number of patients benefit from SM.

Appendix 2: Resources from the project

1. Patient evaluation results:

Table showing comparative data of patient satisfaction levels between Dr led care group and POP Home group.

	Dr Led (n=40) (%)	POP Home (n=21) (%)
Received adequate information	88	100
Involved in the decision to use a pessary	93	100
Received information on the complications	43	81
Understood using a pessary was an alternative to surgery	88	95
Understood could elect to have surgery at a later date	73	90
Felt using a pessary has improved symptoms	90	95
Service convenience	81	95
Aware of who to contact if has problems	88	100
Able to access help	73	100
Feels supported	83	100
Find pessary changes comfortable	53	90
Plan to use a pessary in the long term	71	100
Wanted a named contact person	93	95
Changing my own pessary would/has given greater control of symptoms	86	90
Changing my own pessary would mean I am more likely to continue using a pessary	43	86
Understood would need 6-monthly appointments	85	
Would like written information before decides if would like to self-manage	91	
Would like to learn self-management	49	
Happy to be contacted by telephone rather than attending an appointment	91	
Happy using written information for pessary changes		100
Happy using an online tutorial		57
Telephoned correct number of times		80
Will continue changing a pessary		100

Some specific quotes from patients in the self managing group have been listed below:

- I was relieved that the procedure was not as difficult or distressing as I was expecting. Once I had completed the task I felt confident I would be able to manage it by myself at home.

- Not as bad as I had imagined, in fact it was relatively easy
- It was brilliant! I was not confident, I had tried to do it at home on my own but I couldn't do it. The physiotherapist was patient and put me at ease.
- "Brilliant." So much easier than what I imagined. I have got my life back and I would rather have this control over my own body than have surgery; this I hope I will not need.
- Much easier than I had expected! Compared to recent experiences with trying out contact lenses this was definitely easier!
- As expected, makes changing it easier and more convenient than going to the surgery.
- Enlightening, encouraging and very supportive

2. Patient stories:

Emma's story

Four months after the birth of my first baby, I had a gynaecology appointment because I could feel a bulge in my vagina, which would get worse and more uncomfortable when I exercised or went for long walks. I had tried physiotherapy exercises to improve my pelvic floor, but they didn't seem to be making a difference.

At the appointment I had it explained to me by the doctor that I would need to start using a pessary to relieve my symptoms, and was pleased to hear that I would be able to learn how to change the pessary myself rather than having to make an appointment with the doctor to do it. I went to see Claire straight after my appointment, who taught me how to change the pessary and how to get in touch with her if I had any problems. I changed the pessary for myself with Claire so that we both knew before I went home that I could do it.

I have only ever known self-management as a way of managing my pessary, and when I was told about it I thought it sounded like a very sensible option. As a new mum I can imagine that I would find it really difficult to have to arrange appointments for someone else to change my pessary for me, and I actually found it very easy and comfortable to learn. By changing the pessary myself it also means that I don't feel that I have to rely on it as much. I only use it when I know that I am going to be exercising or doing activities that cause me difficulties. If I was having the pessary changed by a doctor this would mean that I would have to have it all of the time, and I would be worried that I would become dependent on it.

Joyce's story

I had been using a pessary for two or three years before joining the POP Home project, and so had become quite used to having to go into hospital to have it changed, and hadn't thought that there might be any alternative. I found that I would have to go back more often than twice a year, because I often felt like the pessary had slipped. When this had happened I had tried in the past to see whether I could push it back into place myself, but had never been able to and so often had to go back to the doctor before I was scheduled to ask them to re-position it.

Because I had tried to re-position the pessary myself in the past, and not been able to, when my doctor mentioned that I might learn how to change the pessary myself I couldn't see that I would ever be able to do this. I thought there was no way it could work, especially because my GP had tried to change it for me in the past and hadn't been able to so I thought that if he couldn't do it then I definitely wouldn't be able to! But I was so fed up of going into the hospital that I thought it was worth giving it a go- I have a disabled husband and between the two of us we are back and forth regularly, so a few less visits a year was a real incentive. I

went to see Claire, and at first I found it a bit stressful trying to change the pessary myself but she was very patient and made me feel relaxed, so that eventually I was able to do it. Now I tend not to change my pessary unless I feel it slipping, and most of the time I forget that it's even there! I had got to the point of a pre-operative assessment in the past for surgery, but was put off by the possible side effects and long term complications for example difficulty urinating. I have found that having the pessary manages my symptoms, and now that I'm able to change it myself and I don't have to go into hospital regularly it's even more convenient. I really hate coming to the hospital, so for me it's such a positive thing that I don't have to anymore.

Jane's story

I would love to see this service extended to more women, as I think it's been wonderful and is so simple. I had found what I thought was a lump a couple of years ago, and after some investigation I found out that it was a prolapse. I had seen a physiotherapist at the time, who gave me exercises to do so that I could improve my pelvic floor. I did these regularly, but after about a year I found that my symptoms were getting worse so I made another appointment with the physiotherapist.

It was at this appointment that the physio mentioned the POP Home project, and said that if I did use a pessary I might be able to learn how to change it myself. It sounded like a great idea to me so I met with Claire. I can honestly say that I've found the whole concept very enlightening, and really can't fault it. I have found changing my pessary as easy as anything, and am not really considering surgery in the future.

Molly's story

I had been using a pessary for a few years and was having it changed by the sister at my Health Centre. I had never thought that there might be an option to change it myself and so it was just one of those things that I went along for and 'got on' with. Luckily the sister was very efficient at it, although I attend a lot of different appointments and so it's been really nice to be able to tick a couple off the list!

Initially I was a bit daunted by the idea of changing the pessary myself, but once I'd tried it a couple of times I found it OK. The key was to practice, and not to get too nervous. Also once Claire had reassured me that I couldn't put it in the wrong place I felt much happier doing it. Since being able to change the pessary myself I have been taking it out more often than I used to when the nurse did it for me. I like the control that this had given me.

Sarah's story

I was new to using a pessary when my doctor mentioned that I could learn how to change it myself, and so I haven't experienced it any other way. I do feel though that it should be offered to everyone, as it just makes so much sense.

Having a prolapse can be a really sensitive issue for women, and I have seen doctors in the past that I felt were not very supportive. To be empowered and in control makes such a difference to the way that you feel about your condition, and when I met Claire she was so supportive that I left feeling really positive. All I can say is that if you do continue the service, which I absolutely think you should, then you should do it exactly as you've been doing it...including using Claire Brown!

Soon after having my pessary I went to the toilet and it fell out. It struck me then that if I wasn't able to change it myself I would have to call the hospital and make an appointment to go in and have it put back in. I don't know how long I might have waited for the appointment, and whilst I was waiting I would have had to put up with the symptoms of the prolapse. Being able to change it myself was so much better!

Esme's story

I have had a prolapse for a number of years, and up until about two years ago I had coped with it quite well without needing a pessary. In 2012 I had a ring pessary fitted, which I was having changed by my GP. It had been fine for a while, until June last year when I started to have some bleeding. The GP didn't know whether it might be the pessary that was causing the bleeding and so I was referred to Addenbrookes for an opinion, and had the pessary out for about 4 months to give myself a break.

When I saw the doctor at Addenbrookes we talked about whether I should have surgery, but the doctor suggested that I could try using a pessary again and that I might like to try learning to change it myself. I was amazed that I could learn to do this, and was keen to try. I have found that I can take the pessary out quite easily, but I have arthritis and have found it harder to put the pessary back in myself. I also had some more bleeding a couple of weeks ago, so I called Claire and we agreed that I would take it out for a couple of weeks and see how I got on. When it comes to putting the pessary back in, I'm not sure whether I will be able to do this but I will have a go and if I can't do it then I will call my GP and book an appointment for them to do it.

Even though I am finding it difficult to insert the pessary myself, I am so pleased that I am able to remove it. It means that if there are any problems you can take it out immediately- I do seem to have a problem with bleeding and it's good being able to do something straight away, rather than calling the GP and waiting for an appointment. At least if I do need to have a break and then get it re-inserted this is just one appointment rather than two! If anything, I just wish I was a little bit younger so that I could appreciate the service more and be more successful at inserting the pessary myself!

Susan's story

I have had surgery in the past to correct my prolapse. I did this because my mother had used a pessary for years, and she suffered terribly with discharge- I had seen the effect this had on her and really didn't want to go down that route so went straight for surgery. The idea of having to use a pessary was awful for me.

When I went back for my post op follow up the doctor said that they'd not been able to tighten the muscles as much as I'd hoped that they might. He mentioned using a pessary, and could see that I really wasn't keen after seeing my mum's experience. He explained that it might be a while before further surgery was a good idea, and suggested that in the mean time I might just want to learn how to change the pessary myself with Claire. I was quite reluctant, but gave it a go, and was really lucky that I was able to see Claire straight after my appointment- if I'd have had to come back that would have been quite inconvenient. I didn't find it difficult to learn at all.

The good thing about being able to change the pessary myself is that I don't have to have it in all the time. I only use it if I know I'm going to be on my feet for long periods, and otherwise I don't have it in. If I had to have it in all the time I would have gone back to the doctor by now and asked them to take it out, but this way I feel like I'm in control. I am still doing a lot of pelvic floor exercises and so by not having to use it all the time I feel like I'm not becoming reliant on it. I haven't ruled out having surgery again in the future, but at least in the mean time I find this way of managing my prolapse bearable. If I had had to use the pessary all of the time then I don't think I could have coped with using it.

3. POP Home publicity:

<http://www.cambridge-news.co.uk/Health/Health-news/Innovation-earns-Cambridgeshire-health-trust-experts-awards-20130927060053.htm>

<http://www.csp.org.uk/news/2013/10/10/physio-led-gynaecology-programme-boosts-self-management-reduces-demand-surgery>

<http://www.cuh.org.uk/cms/rosie-hospital/departments-services/urogynaecology/pelvic-organ-prolapse/managing-your-pessary>