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Executive Summary

Engaging and supporting patients in the decisions they make about their healthcare is essential for the best health outcomes and most effective use of NHS resources. Throughout the project we have tested our ability as an organisation to introduce Shared Decision Making (SDM) and the use of Patient Decision Aids (PDAs) to our member practices and patients.

Our key finding is that it takes time, energy and perseverance for new ideas and concepts to be understood enough to be useful for patients and clinicians. Clarity and leadership on the strategic direction was essential to sustain us. Communication underpinned all activities.

This report outlines the findings from South Norfolk Healthcare CIC (SNH) participation in the East of England Strategic Health Authority’s ‘Clinical and Staff Perspectives in Shared Decision Making and Information Giving – Pathfinder Project’ which asked the question ‘What does a “patient engaged organisation” look like and how do we get there?’

During the project SNH implemented PDAs within three clinical pathways:
- Localised Prostate Cancer
- Benign Prostatic Hyperplasia
- Osteoarthritis (OA) of the knee

A number of issues to engaging patients within their care were encountered and a number of facilitators to this process identified. This report also includes the findings from a related patient engagement project SNH is undertaking, and summarises this learning into two main areas:
- Implementation – embedding Patient Decision Aids within clinical pathways
- Commissioning – maximising patient involvement their care

Recommendations

1. Clinicians’ understanding and appreciation of SDM and PDAs is reinforced by a multi modal approach to training (live training, e-training, applied training).
2. Patients are partners in their treatment decisions, a key fact most are not aware of. There is a need for a sustained information campaign to raise this awareness.
3. Clinical champions help to motivate the use of PDAs within practices, but it is also necessary to secure buy-in from Practice Managers to adopt a concerted approach to using PDAs.
4. Implementing PDAs within GP practices requires a number of different communication techniques, delivered in a ‘drip, drip’ manner to embed the messages. Issuing easy to use practice implementation packs is also helpful.
5. Patient Groups are key advocates of the SDM process and provide a great conduit for delivering PDAs and core SDM messages to patients within the correct context.
6. Local libraries are an ideal setting to provide patient information. They are able to stock PDAs for members to borrow and offer free internet access and assistance to online tools.
7. Building in physical checks to measure clinician participation can formalise the use of PDAs and serve as a key reminder to initiate the SDM process. These checks can be implemented by using Read codes within clinical systems and introducing tick boxes on referral pro-formas.

8. We need access to more PDAs (on paper, too). Positively: GPs who liked them said they wanted more. Negatively: GPs who were sceptical said ‘what’s the point of spending my time learning about this when so few conditions are covered?’

9. Gathering views from patients via moderated focus groups provides much richer and more immediate feedback than issuing forms or questionnaires.

10. Always review what is going on nationally and get in touch with others. When the going gets hard, a national enthusiast (they almost all are) picks you up and reinvigorates you.

1. Implementation - embedding Patient Decision Aids within clinical pathways

1.1 Implementation approach

The implementation of the PDAs was carefully planned (see Appendix 6). Information was disseminated to a wide range of stakeholders prior to launch. We aimed to support clinicians and practices in the use of PDAs and also enable patients to access these directly and initiate the SDM process themselves.

The implementation covered the following areas:

1.1.1 Research - The pathways we wished to introduce PDAs into were Localised Prostate Cancer, Benign Prostatic Hyperplasia and Osteoarthritis (OA) of the knee. We initially consulted the Cochrane register of decision aids to view available resources. This is an ideal starting point for any organisation wishing to introduce existing PDAs that have been well researched and clinically approved.

The register noted Health Dialog as a supplier of prostate PDAs and we were informed that the prostate PDAs had been developed in conjunction with and East of England Urology project. The project work has moved on and the PDAs are now being managed by NHS Direct and are included within their suite of online PDAs. Unfortunately the move to online versions has meant that the NHS-commissioned hard copy booklets, which include personal decision forms and patient experience DVDs, are no longer being printed. SHN requested the last remaining stock of the PDAs and then financed a small reprint of 1,000 additional PDAs to provide us with a starting stock for the project. This provided us with both hard copy and online PDAs for these pathways.

As Health Dialog do not yet have a UK version of the OA knee PDAs booklets, we were only able to implement the NHS Direct online tool for that pathway.
1.1.2 **Education & Communication** - the introduction of PDAs was supported by a number of education and communication work-streams:

- **Clinical Education Emails** - prior to launch the benefits of SDM and the use of PDAs was a topic of one of our one-screen weekly ‘Clinical Nuggets’ sent out to all clinicians in our member practices. Post-launch, a Clinical Nugget was issued reminding clinicians of the Benign Prostatic Hyperplasia PDA and providing the NICE LUTS guidance.

- **Educational film** - SNH contracted a media company to create a YouTube version of an existing SDM Patient Experience DVD. We presented this to number of our lead clinicians and also added it to our website.

- **Clinical Education Event** - one off event to educate 22 lead clinicians from the 16 participating practices, this included the educational film plus a questions and answers session with the Urology clinicians involved in the original project which created the hard copy PDAs. This event included representation from local patient groups.

- **The SNH website** was launched with general guidance on SDM and PDAs, and details of how to access more specific information.

- A number of GP practice communications were undertaken throughout the project. Prior to launch an email was issued to each practice manager advising of the project and inviting participation. The launch was supported with a Practice Pack, which included a letter to the practice manager outlining the aims of and processes for introducing PDAs. The pack contained a stock of hard copy PDAs, a stock of specially printed business cards which gave patients the websites for the online PDAs, a practice poster detailing which PDAs were available and how they could be accessed (including library information), and an A5 laminate for reception staff which outlined where the PDAs were held, what conditions they were for and how to obtain additional stocks. Each practice manager was then telephoned after the launch to confirm the packs and PDAs were in use and feedback any issues. An updated poster and accompanying email was then issued once the PDAs were launched within libraries, ensuring practices sign-posted patients to these additional resources.

- **Lead consultants within the urology and orthopaedic departments of our main acute hospitals** were advised of the project prior to launch to secure their buy-in. They were also provided with stocks of the relevant PDAs so patient were able to access consistent support tools and information at key stages of the care pathway.

- **Patient communications** were amplified via a support group initiative. We provided the Norfolk and Waveney Prostate Cancer support group with copies of the Enlarged Prostate and the localised prostate cancer PDAs and a SDM Patient Experience DVD. Response was very positive and the DVD particularly valued. Representatives of the group came to the clinician training the library launch events. A strong relationship was built and a website hyperlink established with the group providing a feed into South Norfolk Healthcare’s Shared Decision Making and Patient Decision Aids pages.

- A **Library Launch Event** was planned with the county council and stocks of PDAs were issued to local libraries. The libraries displayed posters and plasma screens informing members of the PDAs and computer support available. Library members are able to borrow the hard copy PDAs and are also given free access to the NHS Direct online tools and the direct free-phone telephone line, along with assistance in using computers.
In addition to advertisement within GP practices, an article on PDAs and their availability in GP practices and libraries in South Norfolk was published in the local press who attended the library launch. Articles were also printed in many of the local parish magazines.

Meetings were held with the local community based physiotherapy service which agreed to sign-post arthritis patients attending multimodal knee classes to the Knee arthritis PDA website and advised them of the library services available.

Discussions were also held with local commissioners on how to formally embed the use of the PDAs within the pathways.

2. Measurement of success

2.1 Clinician survey

2.1.1 Methodology - Two sets of clinicians were surveyed. Set one consisted of clinicians who attended the Clinical Education Event (included a viewing of SDM Patient Experience DVD and Q&A session with John McLoughlin and Jane Thaker). Set two consisted of clinicians who provider referrals triage at SNH (who were provided with an individual viewing of SDM Patient Experience DVD).

The effectiveness of the implementation was gauged by three feedback questionnaires (see Appendix 3, 4, and 5), one before training to establish a baseline, one just after training to measure the changes the third one to measure the implementation outcome after 2 months.

The third questionnaire was administered to eight triagers, (two from set one, three locums, three new triagers). Ideally respondents would have been selected from both set one and set two. Time constraint and holidays were a limiting factor.

Questionnaire 3 presented some inconsistencies, respondents who declared not using PDAs went on evaluating their usage. Invalid answers were set aside.

An email was sent to Practice Managers to request an interview over the phone. Four Practice managers accepted a five minute phone interview.

2.1.2 Results - The results of the first two questionnaires (see Appendix 1 & 2) showed in both sets:
- a marked improvement in the perceived benefit of both SDM and PDAs
- a marked increase in the understanding of both SDM and PDAs
- an increase in the likelihood of using PDAs and SDM
- the increase in the benefit rating of PDAs was higher than the increase in the benefit rating of SDM in both sets
- both sets gave a higher benefit rating to PDA than to SDM

A comparison between the results from the two sets showed:
- set two had a lower baseline in all the ratings than set one
- a remarkably higher increase for all ratings in set two, understanding of both SDM and PDA improved by 126% as opposed to 42% in set one
Questionnaire 3 (see Appendix 3) showed:
- Three out of eight clinicians did not use PDAs
  - One clinician had expressed in questionnaire 2 his uncertainty in using PDAs
  - One was a locum with no previous knowledge of PDA or SDM
- All used it to present patients with various treatment options
- All used it to provide information to patients
- Most used PDAs to find out about patients’ values and personal circumstances
- All the clinicians using PDAs found they helped engage patients in a dialogue
- 3 out of 5 used patient information aids

Practice Manager phone interview results:
- PDAs were distributed by Practice Managers in 3 ways:
  - Consultation rooms
  - Meeting rooms
  - Waiting rooms
- No other channels of communication was used other than the one advised in the Practice Pack
- No mechanism was in place for locums to be informed of PDAs
- Three of the practice managers interviewed said PDAs were used
- One practice manager said PDAs placed in each consultation room were returned to the meeting room unused
- One practice manager put PDA usage on the practice meeting agenda to review its success and found ‘Overall a good response’

2.1.3 Conclusions - All clinicians benefited from the training. Clinicians in set two benefited much more than clinicians in set one. The marked improvement in understanding in set two could be investigated; emails and clinical nuggets sent prior to the Clinical Educational Event and the viewing of the video could be a factor influencing the higher knowledge baseline in set one. Clinicians used PDAs but did not use all their features.

Training had the biggest impact on clinicians’ understanding of SDM and PDA as well as on the rating of their benefit.

There was a mixed response from practice managers. Overall, practice managers were disengaged. Patient Decision aids had a low priority within the practice.

2.2 Patient surveys

2.2.1 Methodology - Patients’ views were sought through:
- An online feedback survey on the South Norfolk Healthcare website.
- A postal survey available on request. Each PDA had a sticker asking for patients’ feedback, contact details and Web address were given.
- Library usage results were requested from library service.
- A PDF of the questionnaire was emailed to the Norfolk and Waveney Prostate Cancer Support Group.
- Online PDA usage results were requested from NHS Direct.
2.2.2 Results

- Two surveys were returned by post from the Norfolk and Waveney Prostate Cancer Group: PDAs were found useful in particular the DVD. Both patients had already been treated.
- ‘Library PDAs Issued’ results for July/August was considered by Norfolk Library Service usage to be encouraging: four libraries issued copies to users. See appendix 6.
- The online survey was viewed 53 times with no survey completed.
- No postal questionnaires were requested.
- Usage of NHS Direct online tools was only recorded if patients created a personal summary and therefore these data did not reflect the actual number of times patients had actually accessed the online tools.

2.2.3 Conclusion - Surveys did not return sufficient feedback from patients. We have to conclude that patients did not regard their experience of PDAs to warrant the extra time taken to fill out a survey. The methods use to seek patients’ feedback will have to be revisited.

3. Lessons Learnt

Converting intention into adoption requires a concerted approach involving all stakeholders, patients, clinical staff, non-clinical staff, and Practice Manager to bring about a change in behaviour.

A much greater level of implementation support is required at practice level. A champion practice manager is key to an effective implementation strategy within practice involving and communicating with non-clinical staff, clinical staff and locums. Practice managers could gain from workshops and information on the benefits SDM and PDAs can bring to a practice.

Locums can themselves introduce Patient Decision Aids as they move from practice to practice and be used as dissemination resources and as agent of change.

Patient Decision Aids are more than patient information aid: a clinician training on ‘how to use PDAs with patients’ would equip a clinician with the skills needed. Support groups are a captured audience with the desire and capacity to draw their members’ attention to Patient Decision Aids. However by the time a patient joins the group he/she may already had his/her treatment or is about to receive it. Support groups web presence can become a conduit to the NHS Direct Patient Decision Aid page. They can also help patients access downloaded copies.

Methods for measuring the use of online tools need to be improved as current available NHS Direct reports do not indicate how many patients from the region accessed the website - this meant it was difficult to gauge how effective different communication strategies had been in terms of directing patients to the online PDAs.

The uptake from patients has been slow: a measured educational approach through parish magazine and newspapers as channels to reach out to the wider public; using libraries as repository; widening the range of PDAs as they become available, could all raise public awareness and usage.
4. Commissioning - maximising patient involvement in their care

4.1 Patient Engagement

SHN is currently undertaking service redesign work on behalf of NHS Norfolk Commissioners in the knee care pathway. We have taken the following approach to embedding the patient voice within this work:

4.11 Discovery - we contracted Picker Institute Europe to initiate a ‘discovery phase’ where patients who have completed the knee care pathway were given the opportunity to discuss how improvements can be made in a moderated focus group setting.

4.12 Measurement - following the discovery stage, a measurement phase will be required to track the effectiveness of changes made to the care pathway. SHN are working with Picker Europe to create patient questionnaires based upon the knee patient focus group outcomes. SNH will initially run the questionnaire in-house and will use it to create a base-line of patient views prior to implementing pathway changes. This will establish the baseline from the discovery phase, the same questionnaire will be repeated after agreed service redesign has taken place and we will measure the effectiveness of the changes in terms of patient experience and satisfaction. We will then feedback to the providers of the service. Our intention is to make this process part of the annual Commissioning for Quality and Innovation (CQUIN) payment framework so we can ensure delivery of changes.

4.13 Formally implementing PDAs - as well as engaging with patients, local services, primary care, secondary care and patient groups, SNH have been working with one of our Community Service Providers, Norfolk Community Health & Care (NCH&C), to pilot the use of the OA knee PDA within the OA knee pathway. We have agreed a more formal process for implementing this decision aid within the OA knee pathway and the following ‘touch points’ have been agreed with NCH&C and NHS Norfolk (NHSN) who commission the service:

- Each participating practice has received the practice pack and education relating to the PDA.
- The referral pathway for suspected OA of the knee contains the flag ‘Ensure Patient has access to www.nhsdirect.nhs.uk/DecisionAids’ within both the Primary Care and the Community Care sections of the pathway map.
- Eligible patients are to be enrolled into Multimodal Knee Classes as part of their conservative management. Each patient attending the classes will be made aware of the NHS Direct website and advised to review it.

NCH&C have created a SystmOne template which will enable the clinicians running the multimodal knee classes to capture their discussions about the OA Knee PDA against each patient record (code Y3496 ‘Patient involvement in decision making’ will be used when a patient has been made aware of the site and its benefits). The use of this code will be included in monthly data set provided to NHS Norfolk as part of the service performance data.
4.2 Including PDAs and SDM in Commissioning Specifications

There are a number of Read codes within SystmOne which denote patient involvement in decision making (parent code X75x6 Decision Making). These include a temporary code, Y3496 Patient involvement in decision making. South Norfolk Healthcare has requested information from Connecting for Health Clinical Terminology Authors to advise on the use of this code and potentially request permanent codes, included ‘Patient Decision Aid given’ to be introduced.

4.3 SystmOne Decision Making Read Codes

![Decision making Read Codes]

4.4 Putting SDM into a contract with a provider

Getting SDM into contracts is absolutely vital. In Appendix 7 we give some sample wording that we intend to work from in future service redesign where SDM is appropriate.
Feedback Questionnaire

Your current views on Shared Decision Making and Patient Decision Aids

Thank you for taking part in this evening’s event. We would like your feedback and would be grateful if you could spend a few moments of your time to complete this form.

Name: _________________________  
Organisation: 
Email: _________________________

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<tr>
<th>On a scale of 1 - 10, how would you rate the following?</th>
<th>Poor</th>
<th>1</th>
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<td>1. How do you rate your understanding of Shared Decision Making?</td>
<td>☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐</td>
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<td>2. How do you rate your understanding of Patient Decision Aids (PDAs)?</td>
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<td>3. How do you rate the benefit of Shared Decision Making?</td>
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<td>5. How likely are you to use Shared Decision Making and PDAs with your patients?</td>
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Feedback Questionnaire (2)
Clinical Education and Development Event

Thank you for taking part in this evening event. We would like your feedback and would be grateful if you could spend a few moments of your time to complete this form.

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<tr>
<th>Please on a scale of 1 - 10, how would you rate the following:</th>
<th>Poor</th>
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1. Now how do you rate your understanding of Shared Decision Making (SDM)?

2. Now how do you rate your understanding of Patient Decision Aids (PDAs)?

3. Now how do you rate the benefit of SDM?

4. Now how do you rate the benefit of PDAs?

5. Now how likely are you to use Shared Decision Making and PDAs?

6. How useful were the resources/materials you were given?

7. How well did the session meet your initial expectations?

Please continue on the other page.
<table>
<thead>
<tr>
<th>Will you be happy to use PDAs in your practice?</th>
<th>☐ Yes</th>
<th>☐ No</th>
<th>☐ Maybe</th>
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<td>Please make any other comments here, including any feedback or suggestions for improvement.</td>
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Many thanks.

Your contribution is very much appreciated.
Appendix 2: Set 2 Questionnaires before and after training (video only)

Feedback Questionnaire (1)
Clinical Education and Development Session

Thank you for taking part in this training session. We would like your feedback and would be grateful if you could spend a few moments of your time to complete this form.

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<th>Please on a scale of 1 - 10, how would you rate the following:</th>
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<td>7. How do you rate your understanding of Shared Decision Making (SDM)?</td>
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<td>9. How do you rate the benefit of SDM?</td>
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<td>10. How do you rate the benefit of PDAs?</td>
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<td>11. How likely are you to use Shared Decision Making and PDAs with your patients?</td>
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Thank you for taking part in this training session. We would like your feedback and would be grateful if you could spend a few moments of your time to complete this form.

Name:

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Please continue on the other page
Will you be happy to use PDAs in your practice?

☐ Yes  ☐ No  ☐ Maybe

Please make any other comments here, including any feedback or suggestions for improvement.

Many thanks.

Your contribution is very much appreciated.
Appendix 3: Questionnaire after PDAs adoption

Feedback Questionnaire (3)
Patient Decision Aids (PDAs)

Last June following the Clinical Event on Patient Decision Aids (PDAs), your practice received a box of PDAs to introduce within your practice. We would like to know how this was received and how it worked for you.

Please take 5 minutes of your time to fill in this questionnaire.

Many thanks.

Usage

Q1. Have you used any of the Patient Decision Aids with your patients?
   Please tick ONE box
   
   • Yes [ ] Go to Q2
   • No [ ] If no can you tell us why you haven’t used PDAs in the box provided below?

Please write any comment here.

Q2. How many Localised Prostate Cancer PDAs were given to your patients?

Q3. How many Enlarged Prostate PDAs were given to your patients?

Q4. How many patients do you think requested a PDA?
Q5. Are you using patient information aids like patient factsheets?
Please tick ONE answer

- Yes □
- No □ Go to Q7

Q6. How do PDAs compare with patient factsheets?
Please tick ONE answer

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Q7. Which PDA features do you value most?
Please tick ALL that apply

- DVD □
- Personal Decision Form □
- Booklet □
- Don’t know □

Q8. How do you introduce the PDAs to your patients?
Please tick ONE that apply

- Give it to the patient to go through it at home □
- Introduce it first with the patient and then give it to them to read at home □
- Other □
  Please specify in the space provided:
Q9. Do you use the PDAs with your patients to:
Please tick ALL that apply

- Present your patient with various treatment options
- Find out about your patient’s values and personal circumstances
- Log the patient’s treatment journey
- Provide information to your patient
- Other
  Please specify:

Q10. Did the PDA help in engaging your patients in a dialogue?
Please tick ONE answer

- Yes
- No
- Don’t know

**Satisfaction**

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<th>How would you rate the following on a scale of 1 - 10:</th>
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<td>16. How useful were the PDAs you were given?</td>
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Q11. Some concerns were expressed at the Clinical Training Event on the 16th of June. Please tell us if the concerns you have using the PDAs are about:
Please tick ALL that apply
- Its impact on appointment time
- Its accessibility
- Its Comprehensiveness
- Its up-to-dateness

Q12. Do you want to be kept informed on new PDAs?
Please tick ONE answer
- Yes
- No
- Don’t know
Appendix 4: Feedback results

Set1 Results: questionnaires before and after group video training with a Q&A session John MacLoughlin and Jane Thaker leading

Set2 Results: questionnaires before and after video training.
Results: questionnaires after PDAs dissemination in GP practices, average

Average set 2 after PDAs adoption

Results: questionnaires after PDAs dissemination in GP practices by respondents

Result sample analysis set 2 after PDAs adoption
Clinicians’ comments on PDAs

Comments - Set 1
Group video training, a Q&A session with John MacLoughlin and Jane Thaker

Respondent 2
PDA’s will need to be updated and take advice from local specialists and services

Respondent 3
Black and white photocopies of these would be horrid. I would prefer a box of hard copies or redirection to a website where it is an animated copy.

Respondent 4
Take a very long time to complete, need internet access for most of them.

Respondent 7
Objective to find out more about PDAs in BPH.

Respondent 8
It would have been more useful to have seen an example of the PDAs that we could use.

Respondent 9
Concern over time in Q1.
Benefit rating Q1: honestly “don’t know”.
Would like a copy of the BPH-PDA.

Q2 useful material: need to take away + digest.

Respondent 11
Too few subjects covered so far.

Respondent 12
Objectives: I felt I should be seen to show an interest?
20mn appointment needed.
Meets half the number of patients.

Respondent 13
In Q1: Too long winded! Pts in Watton want Dr to make decision for them mostly.

Q2 Still seems too long for the majority of our patients. A slightly simpler version would be great.

Respondent 14 (Practice Manager)
Objectives: to collect data pack for review; to understand the pack + data
Good access to NHS direct website.
Respondent 15
The Prostate Cancer PD is far more suited to a hospital environment. As with all of these the information is limited e.g. no data on xxxx to none of 2 of the main areas of treatment also nuances such as consultants advising that radiotherapy at Addenbrookees rather than N/N is better due to differences in machines would not be answered.

Respondent 16
Shocked- all this time, all this hype about 2xPDAs.

(On a separate sheet of paper) I found the information about prostate cancer very interesting BUT there are only 2 booklets-prostate cancers and BPH one on-line knees NHS choice

Respondent 20
Use of SDM and PDAs based on availability.

Respondent 23
I see role for PDAs in BPH.

Comments - Set 2
video training only

Respondent 1: I routinely use freebies available/ PILs from Bupa and Patient.

Respondent 4: My only concern is that there may be some patient groups less able to make use of the material than others- are there translations etc available for specific patient’s needs?

Respondent 2: Did not attend session but saw DVD. Seems to be a hospital based piece of research that might be applicable to GP. We agree that we are good communicators (perhaps better than the hospital docs studied and involve the patient in decision making, but I accept seldom use much written material. I like drawings at the time!)

Respondent 3: I was previously unaware of PDAs though make good use of literature available locally to improve patient involvement; It would be useful to have information in more concise form. I suspect time may be an issue in practice.

Comments after PDAs adoption
Respondent 1: As I have been working as a locum I have not been made aware of those in any of the surgeries I have worked at.

Respondent 3: not sure I tend to consult in a set way perhaps. I use diagrams and explanations+ references as required.
### Appendix 5 Library PDAs Issued

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**Dataset**: 28-Aug-11(P)

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**Total issues**: 12
Appendix 1
Shared Decision Making and Information Giving Pathfinder Project Plan

South Norfolk Healthcare C.I.C. is a community interest company, limited by shares, registered in England and Wales with registered number 07255508.
Our registered office is at The Windmill Surgery, London Road, Wymondham, Norfolk. NR18 0AF
# Shared Decision Making and Information Giving Pathfinder Project Plan

<table>
<thead>
<tr>
<th>ID</th>
<th>Task Name</th>
<th>Duration</th>
<th>Start</th>
<th>Finish</th>
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</thead>
<tbody>
<tr>
<td>81</td>
<td>Design Patient Feedback Form (online version)</td>
<td>7 days</td>
<td>Fri 03/06/11</td>
<td>Tue 14/06/11</td>
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<tr>
<td>82</td>
<td>Upload &amp; test online patient feedback form</td>
<td>2 days</td>
<td>Tue 14/06/11</td>
<td>Thu 16/06/11</td>
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<tr>
<td>83</td>
<td>Design Patient Feedback Form (print version)</td>
<td>8 days</td>
<td>Fri 03/06/11</td>
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<tr>
<td>84</td>
<td>Upload Printed Feedback to website (for download)</td>
<td>1 day</td>
<td>Tue 09/08/11</td>
<td>Tue 09/08/11</td>
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<td>85</td>
<td>Design Clinician Feedback Questionnaire</td>
<td>3 wks</td>
<td>Mon 20/06/11</td>
<td>Tue 16/06/11</td>
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<tr>
<td>86</td>
<td>Design Practice Manager Feedback Questionnaire</td>
<td>2 days</td>
<td>Wed 17/08/11</td>
<td>Thu 18/08/11</td>
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<td>87</td>
<td>Gather Feedback on use of PDAs</td>
<td>47 days</td>
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<td>89</td>
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<td>5 days</td>
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<td>Gather Library usage data</td>
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<td>94</td>
<td>Interpret Feedback on PDA implementation</td>
<td>12 days</td>
<td>Mon 19/09/11</td>
<td>Tue 04/10/11</td>
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<td>95</td>
<td>Analyse feedback on the use of PDAs</td>
<td>1 wk</td>
<td>Mon 19/09/11</td>
<td>Fri 23/09/11</td>
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<td>96</td>
<td>Analyse PDA usage data</td>
<td>1 wk</td>
<td>Mon 19/09/11</td>
<td>Fri 23/09/11</td>
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<td>Draft Report on clinician &amp; patient feedback to PDAs</td>
<td>3 days</td>
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<td>Review Report on clinician &amp; patient feedback to PDAs</td>
<td>2 days</td>
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<td>Fri 30/09/11</td>
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<td>Publish Report on clinician and patient feedback to PDAs</td>
<td>2 days</td>
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<td>Measurable Output 3 - Commissioning</td>
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<td>101</td>
<td>Provide commissioning specifications for primary &amp; community services</td>
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<td>Measurable Output 4 - Minimum Data Set (MDS)</td>
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<td>Research Read Codes available</td>
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<td>Clinical Terminology Author Request logged with CfH</td>
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<td>Discuss new coding requirements with CfH Author</td>
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<td>Request new Read Codes</td>
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<td>Fri 12/08/11</td>
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<td>108</td>
<td>Design Minimum Data Set (MDS)</td>
<td>2 wks</td>
<td>Wed 20/07/11</td>
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<td>Document pathway coding guide</td>
<td>2 wks</td>
<td>Wed 03/08/11</td>
<td>Tue 16/08/11</td>
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<td>110</td>
<td>‘Proof of concept’ report on use of Minimum Data Set</td>
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<td>Wed 23/08/11</td>
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<td>Read Quarterly Meeting (date TBC)</td>
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<td>113</td>
<td>New Read codes available (TBC)</td>
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<td>Fri 14/10/11</td>
<td>Mon 17/10/11</td>
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<td>114</td>
<td>Update pathway coding guide</td>
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<td>Mon 17/10/11</td>
<td>Thu 20/10/11</td>
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<td>115</td>
<td>Final Report Issued to SHA</td>
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7.1. Background information

Shared Decision Making (SDM) is the process of interacting with patients in arriving at informed values-based choices when options have features that patients value differently. Patient decision aids (PDAs) are evidence-based tools designed to facilitate that process. Therefore, they have a potential role in reducing unwarranted variations in the use of ‘preference-sensitive’ health care options.

Many decisions in health care do not have clear answers because the benefit/harm ratios are either scientifically uncertain or sensitive to the value patients place on benefits versus harms. Common examples include options for treating abnormal uterine bleeding, benign prostate enlargement, chronic back pain, and early-stage breast or prostate cancers. John Wennberg and colleagues define these decisions as “preference-sensitive” because the best choice depends on patients’ values or preferences for the benefits, harms, and scientific uncertainties of each option.

When there is no clearly indicated “best” therapeutic option, shared decision making is the process of interacting with patients who wish to be involved in arriving at an informed, values-based choice among two or more medically reasonable alternatives (which may include “watchful waiting”). PDAs are standardised, evidence-based tools intended to facilitate that process. They are designed to supplement rather than to replace patient-clinician interaction. At a minimum, PDAs provide information about the options and their relevant outcomes.

They also help patients personalise this information, understand that they can participate in decision making, appreciate the scientific uncertainties inherent in their choices, clarify the personal value or desirability of potential benefits relative to potential harms, communicate their values to their practitioners, and gain skills in collaborative decision-making.

7.2. Commissioning Environment

Shared Decision Making - ‘No decision about me without me’ clearly presents the need for NHS services to provide patients with timely and effective information and to address the imbalance within the decision making processes concerning patients’ health. The aim is to put patients first and make the principle of Shared Decision Making the norm. The following extract from the report reinforces the value of this approach to patient care:

International evidence shows that involving patients in their care and treatment improves their health outcomes, boosts their satisfaction with services received, and increases not just their knowledge and understanding of their health status but also their adherence to a chosen treatment. It can also bring significant reductions in cost, as highlighted in the Wanless Report, and in evidence from various programmes to improve the management of long-term conditions. This is equally true of the partnership between patients and clinicians in research, where those institutions with strong participation in clinical trials tend to have better outcomes.

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7.3. Commissioning Requirements
The commissioners wish to commission a safe, high-quality service that provides patients and carers with clear, evidence based information and the necessary support to help them make informed choices about their healthcare and increase their awareness of the expected risks, benefits and likely outcomes. The service must be able to demonstrate that patients have been given clear and consistent decision support at each stage of the care pathway.

7.4. Service Vision
The improved services will provide patients with the level of support they need to make the best healthcare choices, based upon their own preferences and values, using clinical guidance and evidence based information. Decisions reached will draw on the expertise of both the patient and their clinicians:

- The clinicians’ expertise on the effectiveness, probable benefits and potential harms of treatment options.
- The patients’ expertise on themselves, their social circumstances, attitudes to illness and risk, values and preferences.

7.5. Changes to Current Services
Successful implementation will require a robust education plan which includes all stakeholders across the entire pathway. Key points within the existing pathways should be identified and clinicians involved must be trained to understand the importance and benefits of deploying Shared Decision Making techniques and tools. Clinicians and patients must have access to SDM tools, such as approved PDAs, to support this process.

Patients should be provided with the relevant PDAs as early as possible in the care pathway to ensure they have time to review and reflect upon these before they make decision related to their healthcare.

7.6. Service Development
When developing the service the provider must:
- Ensure that information given is accurate and of a high quality.
- Engage with other services involved within the pathway to ensure that the information provided is consistent.
- Engage with patients to ensure the information provided is of a type, content and format that meet their needs.

7.7. Service Aim
A fundamental aim of the service is to ensure that patient receive the support required to make informed healthcare choices that are right for their own personal circumstances. The key aims of implementing SDM and PDAs are:

- To embed shared decision making principles within the primary and community care services
- To provide educate all staff to provide a clear understanding of how to apply Shared Decision Making and its benefits
- To provide clinicians with tools to facilitate Shared Decision Making without significantly increasing the time required at each consultation
• To provide patients with the right level of information at the right time in their care
• To improve the quality and effectiveness of patient consultations
• To empower patients to make informed choices that are right for them
• To improve patient experience of and involvement in their own care
• To increase patient satisfaction

7.8. Community Engagement
The provider(s) must ensure that they have plans to carry out the following as a minimum:
• Provide information to all patients on the Patient Decision Aids available
• Provide an opportunity for patients to make comments, compliments and complaints at all times and for there to be a mechanism for the provider(s) to respond, review comments and discuss developments or corrective action.
• Carry out internal quality checks to ensure staff are complying with the principles of Shared Decision Making and patient information giving

The provider(s) will demonstrate their plans to liaise with potential key service users on at least an annual basis to gain their views on access to and content of patient information given and feedback from this exercise should be made available to inform improvements.

7.9. Expected Outcomes
By systematically implementing PDAs within the service at relevant points in patient care pathways, the following benefits are expected:
• Reduction in unwarranted variation in terms of treatment options chosen and service utilisation.
• Increased patient satisfaction
• Increased patient knowledge
• Increased patient confidence
• Improved adherence to treatment recommendations

7.10. Quality of Information Provided
The development of the service delivery model to provide improved patient information and decision support must also ensure that the information provided is correct and up to date. The provider(s) will ensure that information provided is regularly reviewed and revised as appropriate.

7.11. Continuous Quality Improvement
The service will be expected to take part in regular reviews to ensure quality assurance and identify any gaps in service provision. Feedback from patients, clinicians and other service stakeholders will also be used to provide continuous improvement to the patient information provided and the processes by which it is disseminated.

7.12. Professional Competency, Education and Training
All staff involved in delivering the service must have an appropriate understanding of which PDAs exists, their aims and benefits and how they can be accessed.
7.13. Performance Reports Format

The standard performance reports to be issued by the provider(s) are summarised below:

- Shared Decision Making initiated by health professional
- Number of Patient Decision Aids disseminated
- Patient experience report
- Quality Audit report

7.14. Data Reporting Tools

<table>
<thead>
<tr>
<th>Target indicator</th>
<th>Measurement tool</th>
<th>Reporting frequency</th>
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<tbody>
<tr>
<td>Patient experience</td>
<td>Approved questionnaires / interviews</td>
<td>Quarterly</td>
</tr>
<tr>
<td>Shared Decision Making initiated</td>
<td>Audit of clinical records*</td>
<td>Quarterly</td>
</tr>
<tr>
<td>Patient information provided</td>
<td>Audit of PDA stock</td>
<td>Quarterly</td>
</tr>
<tr>
<td>Value for money</td>
<td>Cost per PDA provided</td>
<td>Quarterly</td>
</tr>
</tbody>
</table>

7.15. Implementation Plan

The provider(s) will provide the Commissioner with an implementation plan, which demonstrates how they will introduce the PDAs across the chosen care pathways.

The implementation plan shall include a detailed timed program for achieving certain key identified milestones. As a minimum, this will include the detailed plans for:

- Engaging with patient groups and receiving feedback on the PDAs
- Finalising the PDAs to be included in the service
- Educating clinicians and staff on the use and benefits of the PDAs
- Educating clinicians on how to code the initiation of Shared Decision Making within their clinical system
- Engaging related services and informing them of the PDAs being implemented
- Patient communications which include informing all patients of the PDAs in use and how to access them
- PDA management processes, which include stock control of physical items and clinical review of content.
- Measuring patient experience - finalising questionnaires and mechanisms for deploying them

* There are a number of options for measuring the instances when a clinician or other health professional issues a PDA and initiates Shared Decision Making with a patient. The following options can be utilised to provide statistics which can be included within the performance reports:
  - Inclusion of a clinical Read code on the electronic patient record when a PDA has been issued/discussed (see Relevant Read Codes section) - this count could be extracted by system reporting tools
  - Inclusion of Personal Decision Forms within clinical notes - this count would only be extracted via physical audit of patient records
  - Inclusion of a checkbox within an onward referral form, indicating whether the clinician has provided a the patient with the PDA either before or at time of referral - this would be extracted by an audit of referral pro formas received by related service provider(s)
End notes

i http://decisionaid.ohri.ca/AZlist.html


